Your guide to

OSTEOSARCOMA

Trusted Information Creator
Patient Information Forum

BONE CANCER RESEARCH TRUST

Just diagnosed with osteosarcoma?

Hearing that you have cancer is scary and there will be lots to take in. We feel that it's important for you to understand your diagnosis. This might help you feel more in control and understand more about what is happening to you.

It's easy to think that only older people get cancer because over half of the people who get cancer are over 65 years old. But some types of cancer mainly affect children, teenagers and young people. Osteosarcoma is one of these.

This booklet has been written for people aged 16 to 24 years old to explain:

- what osteosarcoma is
- what treatments you may have and how they may affect you
- ways to help you cope with side effects
- how you may feel
- what happens after your treatment

However, you might be older or younger than 16 to 24 years old and find this booklet useful.

The Glossary on page 38 explains medical words and terms relating to osteosarcoma that you may not have heard before.

If you would prefer to read a summary of the key points in this booklet, you can request a copy of our osteosarcoma leaflet by:

- Calling our Support and Information Team on: **0800 111 4855**

- Downloading it from our website: **bcrt.org.uk/download**

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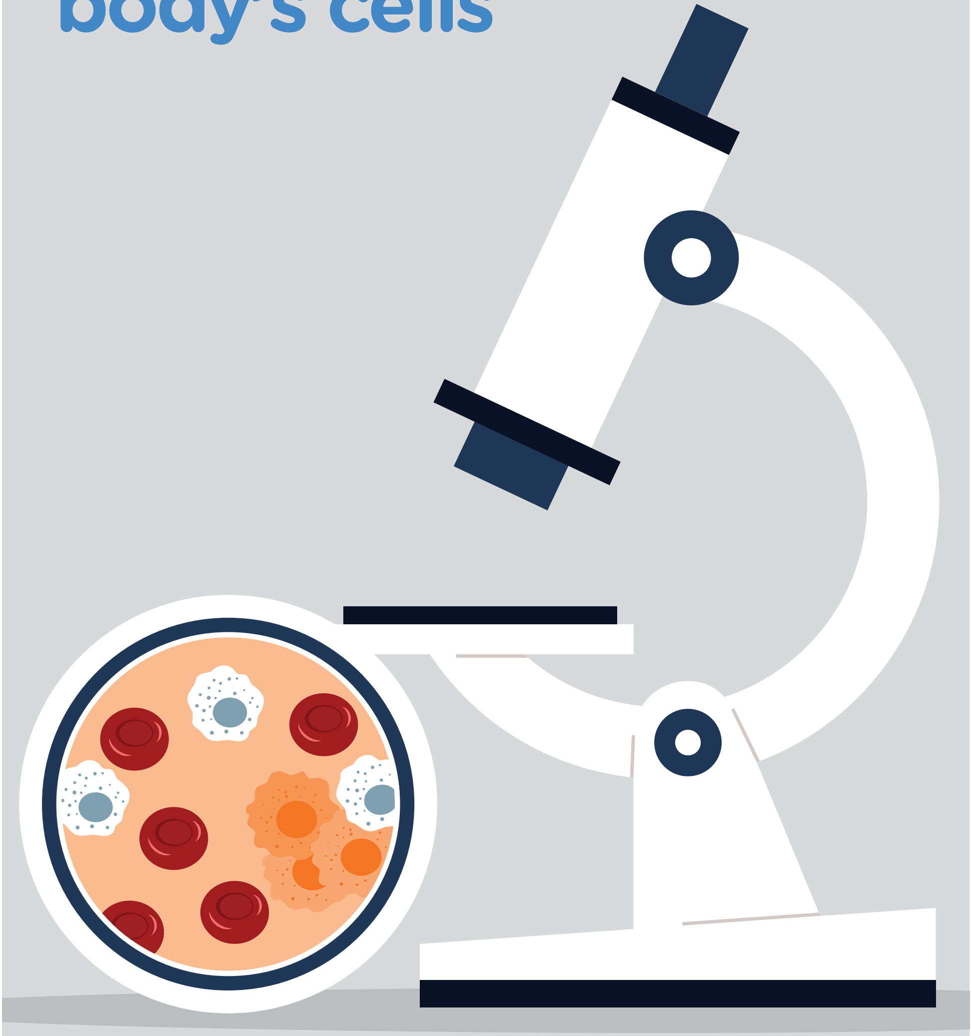
Hearing that you have cancer is scary and there will be lots to take in. This booklet is here to help you, as and when you need it.

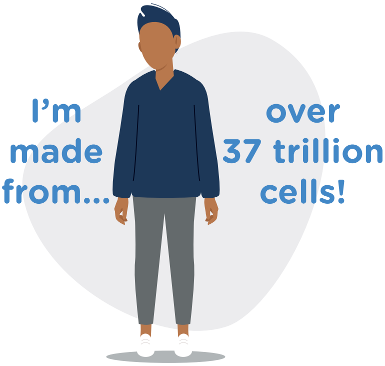
Cancer is a disease of the body's cells



Cells

What is a cell?

All living things are made up of cells. Cells are the building blocks for tissues and organs that make up our bodies. Each human being is thought to be made of trillions of cells.



During development, growth and when the body needs to repair itself, new cells need to be made. New cells are made when one cell splits into 2 to form 2 new exact copies. These are called 'daughter cells' and we call this 'cell division'.

The process of cell division is very tightly controlled. This means new cells are only made when they are needed. Each cell has a set of instructions that tells it what type of cell it is and when it should divide. We call these instructions 'genes'. Genes are made up of what is called 'DNA'.

What is cancer?

If cells start to divide in an uncontrolled way, they can form a growth, called a tumour. These cells can also invade and damage other tissues or break away from the tumour and spread to other parts of the body. When this happens, the growth or tumour is called 'malignant' and we call this disease 'cancer'.

Certain genes tell a cell when to start and stop dividing and when to die. If these genes are damaged, the cells will keep living and dividing, making more cells.

- Primary bone cancer is the name given to cancer that starts in the bones.
- Secondary bone cancer is the name given to cancer that has spread to the bones from other parts of the body.

Cancer is not a single disease. There are over 200 types of cancer that affect different organs and tissues.

Bones

About primary bone cancer

Each year, around 560 people in the UK will be told they have a primary bone cancer.

- Around 160 out of the 560 people with primary bone cancer have osteosarcoma.
- More than 1 in 3 people diagnosed with primary bone cancer in the UK are under 29 years old. So, you're not alone in this.

Bones feel like stone to touch. How can they get cancer?

Bones seem to be hard and rock-like, but they are living things. They contain cells, nerves and blood vessels just like other parts of the body. Your bones change as you grow and as your body changes over your lifetime.

Your bones grow in the same way as the rest of your body, by cells dividing. When cells divide, they make copies of themselves but sometimes things go wrong. If things go wrong, the cells in the bone can grow in an uncontrolled way. This can cause primary bone cancer, like osteosarcoma.

The picture on page 7 shows the different parts of a bone where osteosarcoma may start.

The hollow centre of some bones is the place where bone marrow is made. Bone marrow makes blood cells. People can get cancer which starts in the bone marrow, like 'myeloma', 'leukaemia' and 'lymphoma'. Doctors do not classify these as primary bone cancers.

If you need information on these types of cancer please:
Visit: bloodcancer.org.uk
Call: 0808 2080 888

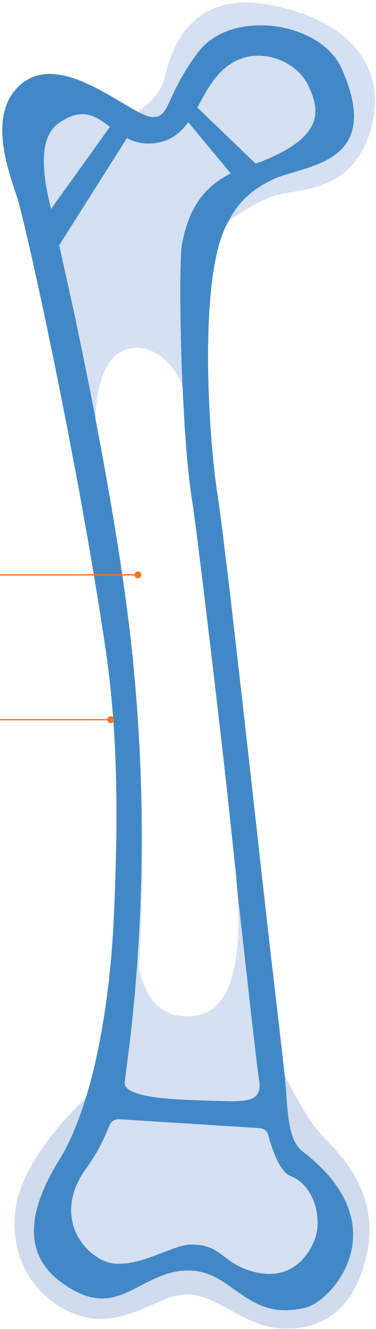
Bones:

- Give us shape and support.
- Protect our body.
- Help us move.
- Store minerals.
- Make cells that move around our body in the blood.

Did you know?

Bone sarcoma is another term for bone cancer.

Parts of the bone where osteosarcoma may start



Medullary Cavity

Periosteum

Protective layer where ligaments and tendons join to bone

Osteosarcoma

My friend has bone cancer but it's not the same as mine. Is there more than 1 type?

Yes, there are different types of primary bone cancer.

There are also many different types of bone tumour which are different to bone cancers.

We provide information on all types of primary bone cancer. You can find it on our website: **bcrt.org.uk/information**

Or you can call our Support and Information Team on **0800 111 4855.**

You can also ask your doctor or nurse for information.

I've been told I have osteosarcoma. What is it?

Osteosarcoma is a type of primary bone cancer. This means that it starts in the bones. In very rare cases, it may start in soft tissue, like the muscles.

Osteosarcoma is:

- the second most common type of primary bone cancer
- the most common type of primary bone cancer found in children and young people

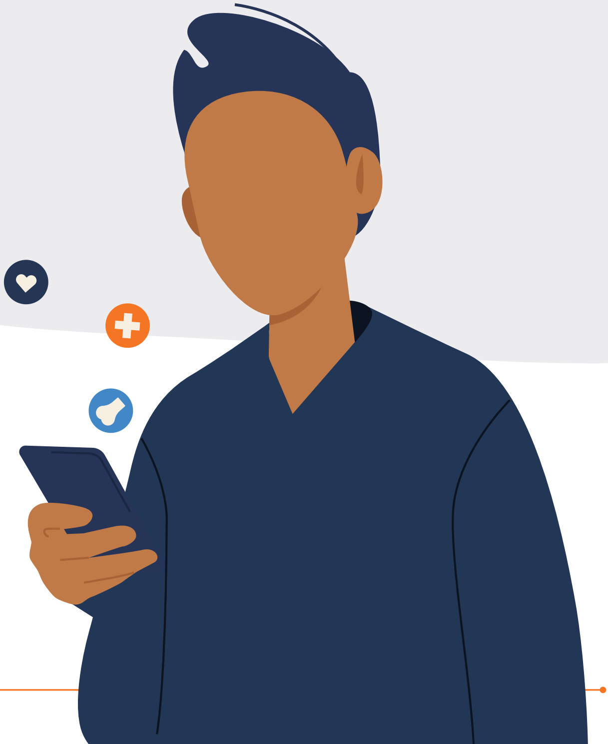
Most cases of osteosarcoma are found in people between the ages of 10 to 24 years old and over 60 years old.

- Each year in the UK around 160 people are diagnosed with osteosarcoma.
- Osteosarcoma is slightly more common in males than females.

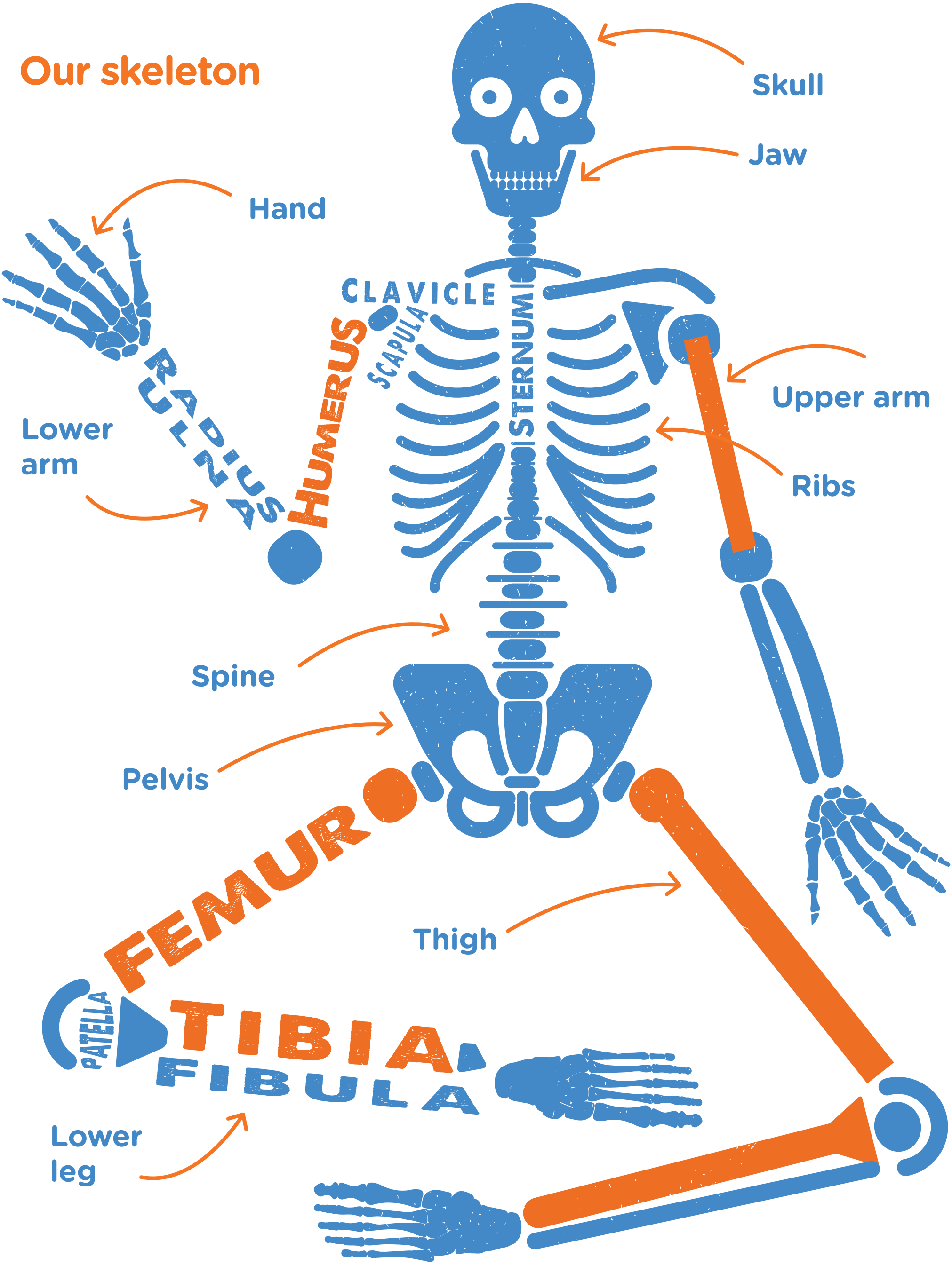
Did you know?

The word 'osteo' comes from an ancient Greek word for 'bone'.

Visit
bcrt.org.uk/osteosarcoma
to find out more



Our skeleton



What parts of the body can osteosarcoma affect?

The skeleton picture shows which bones of the body osteosarcoma may start in.

The most common places are the:

- lower thigh bone near the knee (distal femur)
- upper shin bone near the knee (proximal tibia)
- upper arm bone near the shoulder (proximal humerus)

These are shown in orange on page 10.

Around 1 in every 100 osteosarcomas start in more than one bone at the same time. This is called ‘multi-focal’ osteosarcoma.

Is everybody’s osteosarcoma the same?

No, there are different types of osteosarcoma. The type depends on where in the bone it starts, what the cancer cells look like and how they behave.

The 2 main types of osteosarcoma are central osteosarcoma and surface osteosarcoma:

Central osteosarcomas start in the hollow, central part of the bone called the ‘medullary cavity’. 95 in 100 people with osteosarcoma will have a central osteosarcoma.

There are different sub-types of central osteosarcoma:

- Conventional osteosarcoma. This is the most common. 75 in every 100 people with osteosarcoma will have conventional osteosarcoma. It is high grade.
- Telangiectatic osteosarcoma, Small cell osteosarcoma and Giant Cell Rich osteosarcoma (GCRO) are all rare types of central osteosarcoma. They are high grade.
- Low-grade central osteosarcoma is a rare type of central osteosarcoma. It is low grade.

Surface osteosarcomas start on or near the surface of a bone. There are 3 sub-types of surface osteosarcoma:

- Parosteal osteosarcoma
- Periosteal osteosarcoma
- High-grade surface osteosarcoma.

They are all rare. Around 5 in 100 people with osteosarcoma will have a surface osteosarcoma.

There are also different ‘grades’ and ‘stages’ of osteosarcoma:

- **Grade** is how the cancer cells look under a microscope. The grade can be used to predict how quickly the cancer might grow and spread. High grade cancer cells look very abnormal. They are likely to grow and spread more quickly than low grade cells.
- **Stage** is how big the tumour is and if it has spread to other parts of the body.

Your doctor will talk to you about the type, grade and stage of your osteosarcoma.

How did I get osteosarcoma?

Doctors do not yet fully understand why some bone cells become abnormal and grow out of control. In most cases, the cause of osteosarcoma is not known.

There are things called 'risk factors' that put some people at a higher risk of getting osteosarcoma. They include some rare inherited conditions that are passed on from parents: Li-Fraumeni syndrome, Rothmund-Thomson syndrome, Werner's syndrome and inherited retinoblastoma. Inheriting a damaged copy of a gene called '*RB1*' is also a risk factor, so is previous radiotherapy treatment.

We do know that:

- you cannot catch osteosarcoma from anyone else
- there do not seem to be any environmental factors that cause osteosarcoma, such as radiation
- osteosarcoma is not caused by something you have done

How will osteosarcoma affect me?

When a person has an illness, doctors try to predict how it will affect that person. For example, how likely it is that the treatment will work, and how likely it is that the person will be cured. This is called a 'prognosis'.

Lots of different things are taken into account when doctors make a prognosis for osteosarcoma. The main ones are:

- what the osteosarcoma tumour cells look like under a microscope
- where in the body the tumour is. This can affect which treatments will work best
- the size of the tumour
- the age and general health of the person
- if the osteosarcoma has spread (is metastatic)
- how the tumour responds to treatment

Remember that everyone is different. This means doctors can never be sure how osteosarcoma will affect you.

Diagnosis

How will doctors know if I have osteosarcoma?

Doctors will carry out some tests to find out if you have osteosarcoma. They will answer 2 questions by doing these tests:

- what is it?
- where is it?

What is it?

X-rays and scans may show that you are very likely to have osteosarcoma. To be sure, doctors will collect a small piece of the tumour. It will be sent to a special lab where the cells in the tumour can be looked at under a microscope. This is called a ‘biopsy’.

By looking at the cells, a doctor called a ‘pathologist’ can tell if you have osteosarcoma. They will also be able to find out the type and grade of the cancer.

Where is it?

X-rays and scans of the tumour and body help doctors to see the size of the tumour and exactly where in the body it is. The scans also show the doctors the stage of the cancer.

If a cancer has spread away from the original (primary) site it is called ‘secondary cancer’. Doctors call these secondary tumours ‘metastases’.

Osteosarcoma can sometimes spread to other parts of the body. The most common part of the body it spreads to is the lungs. This is called ‘pulmonary metastasis’. It can also spread to other places in the body, including other bones.

It is important for doctors to understand the grade and stage of cancer. They can then choose the best treatment options for you.

Treatment

Where will I be treated?

Where you are treated will depend on where the cancer is, how old you are and a number of other things.

You will usually be diagnosed and usually have your surgery at a bone cancer centre. These are special centres where a group of people who are experts in bone cancer will discuss and manage your care together. This group of people is called a ‘multi-disciplinary team’ (MDT).

- In England, there are 5 bone cancer centres: Birmingham, Newcastle, Oswestry, Oxford, and Stanmore (North London).
- In Wales, there are no bone cancer centres. People are usually seen at Oswestry or Birmingham.
- In Scotland, there are 3 bone cancer centres: Glasgow, Edinburgh and Aberdeen. For more information, visit the Scottish Sarcoma Network website: **nn.nhs.scot/ssn/about-us/our-centres/**
- In Northern Ireland, there is a bone cancer centre in Belfast.

The bone cancer centres are shown on the map on page 15. You may have to travel a long way to get to a bone cancer centre.

Other treatments for osteosarcoma such as chemotherapy (also called ‘chemo’) and radiotherapy can take place at different hospitals around the UK. Your MDT will decide where you are treated.

Who will I be treated by?

You will be treated by a ‘multi-disciplinary team (MDT). The team will include oncologists (doctors who care for people with cancer), surgeons, nurses, social workers, dieticians, physiotherapists, and many other experts.

You will have a Clinical Nurse Specialist (CNS), sometimes called a ‘key worker’. They are there throughout diagnosis and treatment to give support and listen to questions or worries you may have.

As well as the MDT, you may also have a care team at your local hospital and community nurse support. This will depend on where you live and what treatment you have.

Bone cancer centres in the UK

Aberdeen
Aberdeen Royal Infirmary

Belfast
Musgrave Park Hospital

Birmingham
The Royal Orthopaedic Hospital NHS Foundation Trust

Edinburgh
Edinburgh Royal Infirmary

Glasgow
Glasgow Royal Infirmary

Newcastle
North of England Bone and Soft Tissue Tumour Service, Newcastle upon Tyne Hospitals NHS Foundation Trust

Oswestry
The Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust

Oxford
Nuffield Orthopaedic Centre NHS Trust

Stanmore
Royal National Orthopaedic Hospital NHS Trust

Types of treatment

There are different treatments for osteosarcoma. Everyone will have a slightly different treatment plan.

Some treatments are called ‘local’, and some are called ‘systemic’.

- Local treatment includes surgery and radiotherapy.
- Systemic treatment includes chemotherapy.

For osteosarcoma that is ‘high grade’, the standard treatment in the UK is chemotherapy and surgery. Radiotherapy is only used in some people if surgery is difficult, or not possible.

For osteosarcoma that is ‘low grade’, you may only have surgery.

Your medical team should talk to you about the different treatment choices and what is involved. Treatment of cancer should involve you and your doctors working together to find the best care or treatment plan.

Before treatment starts:

- ask your doctors any questions you have about your treatment plan
- you will have blood tests and other tests to check how well your heart, kidneys and liver are working. This is because some of the medicines used to treat osteosarcoma can affect these organs

Chemotherapy

Chemotherapy, sometimes called ‘chemo’, is a systemic treatment for osteosarcoma. It travels around the whole body through the bloodstream. Your chemo will probably start soon after you have been told you have osteosarcoma. You may have chemotherapy before and after surgery.

Chemo given before surgery is called ‘neo-adjuvant chemotherapy’. The current standard chemo treatment for osteosarcoma before surgery is made up of 3 chemo medicines. They are methotrexate, doxorubicin and cisplatin. Together, these medicines are called ‘MAP’. They are given over 10 weeks. The medicines are given together so that if one doesn’t work very well, the others may still destroy the cancer cells. The aim of chemotherapy before surgery is to shrink the tumour and destroy any cancer cells that could have spread from the original (primary) site to other areas of the body.

After the tumour is removed by surgery, some people will have more chemo. This is called ‘adjuvant chemotherapy’. The same 3 ‘MAP’ chemo medicines will be given (methotrexate, doxorubicin and cisplatin). They are usually given over 20 weeks. The aim of chemo after surgery is to destroy any remaining cancer cells and lower the chance of the cancer coming back.

Other chemo medicines may be used if MAP does not work well or if the cancer comes back. These medicines are called ifosfamide, etoposide, gemcitabine and docetaxel.

How will I be given chemo?

For osteosarcoma, you will be given chemo directly into your blood by intravenous infusion (I.V.). The medicines are given through a central line. A central line is a long, flexible, plastic tube that goes into a vein in the chest or arm. An infusion is a way of giving a dose of I.V. medicines such as chemo over a set period of hours or days. The medicine 'drips' into the blood slowly.

The infusion can also be controlled by an infusion pump, which is connected to a central line. Some of the pumps are small enough to fit in a pocket. This means you can use them at home.

Central lines can be kept in for weeks or even a few months. Using these lines means you don't need as many needles during treatment. It also means more than one medicine or treatment can be given at the same time. For example, fluids and nutrition.

There are different types of central line. They are all slightly different. Your doctor and nurse will talk to you about which type is best for you.

Chemo is given in 'cycles.' A cycle is the treatment time plus resting time. For example, you may be given chemo medicines over 5 days and then there may be a resting period of 2 days. This means the cycle is 1 week. The resting period helps the healthy cells recover before the next treatment cycle begins.

How does the chemo know which cells are cancer?

Cancer cells divide and grow quickly, so chemo medicines were made to target cells that divide quickly. Different chemo medicines affect different parts of cells and that is why more than one medicine is usually given. This is called ‘combination chemo’.

What about side effects?

Most healthy cells do not divide quickly. However, hair follicle cells, skin cells, bone marrow cells, and those lining the digestive tract (where food moves through the body) do. This means chemo can also affect these healthy cells and this is what causes side effects. The side effects should go away when the chemo is finished.

When doctors tell you the list of possible side effects, remember that you might not get any of them. You might only get some of them. If you don’t have the same side effects as other people having the same chemo, don’t worry. This doesn’t mean your treatment is not working. Everyone is different.

The best people to talk to about side effects and how to cope with them are your doctors, nurses and other young people who have had chemo treatment for cancer.

Read the following pages for information about the most common side effects of chemo and tips for managing these.

Feeling and being sick

The doctors can give you anti-sickness tablets to help stop you feeling sick (nauseous) or being sick (vomiting).

Try not to eat very strong flavoured food or fried greasy food. Eating small meals more often will help. Watching TV whilst eating can help take your mind off any sickness you feel.

Low levels of white blood cells (neutropenia)

Before and during treatment you will have regular blood tests to check levels of special blood cells called ‘neutrophils’. Neutrophils are white blood cells that help protect against bacterial infections.

Chemo can lower the number of neutrophils in the blood. This can cause a condition called ‘neutropenia’ which increases your risk of getting infections.

It is very important that you know what to do if you get a high temperature (fever) while having chemo. This can be a sign of infection. Your MDT will give you a contact number at the hospital to call if you get a temperature.

If this happens it is very likely that you will be asked to go to the hospital for a blood test and see the oncologist. You will be given antibiotics to fight off an infection if you have neutropenia. You may need to have small injections under the skin called G-CSF. This is to help the neutrophils recover after chemo.

Lack of energy (fatigue)

Lack of energy, also called ‘fatigue’, is the most common side effect of chemo and other cancer treatments. Fatigue is different from tiredness. We all get tired but fatigue is a feeling of lacking energy when we shouldn’t really be. And it doesn’t seem to go even after a long sleep. Fatigue can also be caused by not having enough red blood cells. This is another side effect called ‘anaemia’.

There is a medicine that doctors can give you to help with fatigue. You may have a blood transfusion if your fatigue is caused by anaemia. Research has shown that exercise and keeping active can help with fatigue. Resting all the time makes it worse. Plan something to do to stay active. Maybe you could go for a walk or go shopping with friends or family.

Sore mouth

Mouth ulcers can be a side effect of chemo. They can make it difficult or unpleasant to eat. Doctors can give you mouthwashes and gels that can help. Brushing your teeth often with a soft toothbrush will also help to keep your mouth clean. Sucking ice cubes or eating ice cream may also help.

Taste changes

You may find that you have a taste of metal in your mouth or that your favourite foods taste horrible, salty or bitter. Don't worry, this will stop once the chemo is over. Using plastic spoons, knives and forks may help to reduce the taste of metal.

Adding herbs and spices to food and avoiding food that doesn't have much flavour may also help. Talking to a dietician is also a good idea.

Weight changes

During treatment, you may not feel like eating and start to lose weight. It's important to keep your weight as stable as you can, calories are really important. Try and eat as much as you can, when you can.

It's also important to eat a healthy diet. Eating a variety of foods means you can get all the energy, vitamins and minerals you need. This will help your body and keep your immune system working well.

The Children's Cancer and Leukaemia Group (CCLG) charity have a booklet called 'Help your child to eat well during cancer treatment'. You can find it on their website:

Visit their website:
cclg.org.uk/publications
or call them on:
0333 0507 654

Hair loss

This is the side effect of chemo that most people know and ask about. Hair loss can begin from a few days to a few weeks after starting chemo. You may lose some or all of your hair, even eyebrows and pubic hair.

Some people may not care about losing their hair. Others may feel upset or scared about it. Try to stay positive and remember your hair will grow back. Talking to your nurse about hair loss may help.

You may feel you want to wear a head scarf, cap, hat or a wig. You may just want to bare all by shaving your head before the hair loss starts! You could even raise some money for charity or your hospital by being sponsored for your head shave.

The Little Princess Trust may be able to help you get a free wig. Contact them to find out more:

Visit their website:
littleprincesses.org.uk
or call them on:
01432 760 060

Surgery

Surgery is a type of ‘local’ treatment for osteosarcoma. After chemo, most people with osteosarcoma have surgery to remove the main tumour. The aim of surgery is to completely remove the tumour and keep the body working as normally as possible. The multi-disciplinary team (MDT) usually decide if surgery is possible. The team includes expert surgeons.

The type of surgery will depend on:

- where the tumour is
- the size of the tumour
- whether the tumour has grown into nearby tissues or spread to other parts of the body

For some people, it is very difficult to remove the tumour. Such as if it is in the pelvis, spine, skull or jaw. In this case, radiotherapy may be used instead. You can read more about radiotherapy on page 24.

If your osteosarcoma is in a limb (arm or leg), your doctor will do their best to save the limb by doing ‘limb-sparing surgery’. This is not always possible and they may need to remove whole or part of the limb. This is called an ‘amputation’. You can read more about this on page 22.

If the tumour has spread to other parts of the body, your oncologist and surgeon may want to think about removing these secondary tumours too.

Your surgeon will talk to you and explain what type of surgery is best for you. You can ask as many questions as you like. There’s no such thing as a silly question, so if something is worrying you or there’s something you don’t fully understand, just ask.

I’m having limb-sparing surgery. What does that mean?

This is where the whole tumour is removed from your limb. This means your limb is ‘spared’. It is replaced with a piece of bone from another part of the body or from another person (a bone graft). In some people, part or all the bone is replaced with a metal implant called an ‘endo-prosthesis’. The implant may be a complete joint if the tumour was near a knee, hip or shoulder.

Rehabilitation after limb-sparing surgery

A physiotherapist will visit you to talk about what will happen before and after the operation, and about rehabilitation (also called ‘rehab’).

Rehab is the process of making your body stronger after the operation and learning to live with the changes to your body. The physiotherapist will give you some exercises to do every day before the operation, to help you strengthen your muscles.

You will start rehab very soon after surgery. The physiotherapist will get you to do lots of exercises to strengthen the limb and get you moving again.

You will also have regular check-ups with your surgeon. They will check how you are recovering and that the implant or bone graft is working well. They will also check for signs of infection.

The doctor says I can’t have limb-sparing surgery. Why?

Sometimes it is not possible to remove a bone tumour from an arm or leg. In this case, limb-sparing surgery will not work, and an ‘amputation’ may be needed instead. This is when all or part of an arm or leg is removed.

An amputation may be needed if the tumour:

- has grown into important nerves and, or blood vessels
- is in a place where the arm or leg would not work properly after limb-sparing surgery

Your medical team will talk to you about whether an amputation is the best treatment for you.

What happens after an amputation?

After the amputation, you will need to wait for your stump (the part of the limb that is left) to heal and the swelling to go down. This can take a few months. You might then be fitted with a prosthetic arm or leg, called a 'prosthesis'.

You will start rehab very soon after surgery. Your physiotherapist and occupational therapist will work with you to keep you moving as much as possible. They will get you ready for wearing and using your prosthesis.

You can visit our website to watch videos about amputation:
bcrt.org.uk/amputation

Mepact (mifamurtide)

Some people aged between 2 and 30 years old may be given a medicine called 'Mepact' or 'mifamurtide'. It is given with chemotherapy, after surgery. It helps white blood cells in the body attack any cancer cells that may be left.

Mepact is only approved for use in people aged 2 to 30 years old with high grade osteosarcoma that has not spread. This means studies and trials have shown it is safe to use in this group of people only.

Radiotherapy

Radiotherapy means treating the tumour with high doses of concentrated radiation. It is not often used to treat osteosarcomas. It is not as good as chemotherapy at destroying osteosarcoma cells.

However, it may sometimes be used:

- after surgery, if the whole tumour is not removed
- instead of surgery, if the tumour cannot be removed by surgery

Your medical team will decide on the dose and how long radiotherapy treatment will last.

Proton Beam Therapy

Proton Beam Therapy (PBT) is a type of radiotherapy. It delivers high dose radiation to the tumour, to destroy the cancer cells. Healthy tissue around the tumour is less likely to be damaged by PBT, than standard radiotherapy. This means there may be fewer side effects.

Only a small number of people will be eligible for PBT. Your doctor will talk to you if they feel PBT will benefit you. In the UK, PBT is only available at The Christie Hospital, Manchester and at University College London Hospital, London.

Setbacks

I keep getting infections and other setbacks. Is my treatment working?

Setbacks are normal. During your treatment, things may not always go as smoothly as the doctors, and you would like. There may be times when you feel really unwell, get an infection or need to have more surgery.

Try not to worry, all these things are a normal part of cancer treatment.

It doesn't mean that your treatment isn't working. You may wonder why your friend on the ward doesn't get infections or the same side effects as you. Just remember, everyone is different.

During your treatment if you feel up to it, plan a day with your friends or a special treat. Have some fun.

Clinical trials

The doctors may talk to you about clinical trials. Clinical trials help scientists and doctors find out the best ways to treat osteosarcoma. They are important in developing new treatments or improving tests to diagnose osteosarcoma.

Taking part in these trials can involve different things; from answering a few survey questions, to trying out a new drug or treatment to test if it is better than the usual treatment.

Before a clinical trial starts, the treatment or test included in the trial will have been investigated. It will have been through strict tests in a lab, called 'pre-clinical studies'. It may also have been involved in clinical trials already.

Taking part in a clinical trial

A doctor may talk to you about a clinical trial, or you and your family may find out about one yourselves. It is very important that you speak with your doctor before joining a clinical trial. They will help you understand if you are able to take part and answer any questions you may have.

If you are thinking about taking part in a clinical trial, we encourage you to look at the information we provide on our website: **bcrt.org.uk/information/clinical-trials**

Pros and cons

There are many things to think about when looking into taking part in a clinical trial. Like if you need to travel to the clinical trial centre, or join a waiting list for the trial.

The treatment you have during a clinical trial may or may not be better than the usual treatment. This is what the trial is trying to find out.

During clinical trials people are monitored closely and this often means that any changes to their health are picked up sooner and they may see better results. This also means people on a clinical trial will need more check-ups and tests than usual, and need to visit the hospital more often. This can be difficult for some people but knowing they may be helping other people in the future can be a great bonus and a positive reason for lots of people.

You can leave a clinical trial at any point. This will not affect the care and further treatment you have.

We provide information about clinical trials and what it means to take part in a trial. We also have a list of trials available for bone cancer patients.

You can find this information on our website at: **bcrt.org.uk/clinicaltrials**

You can also contact our Support and Information Team for more information:

Email: **support@bcrt.org.uk**
Call: **0800 111 4855**

Worries

After being told you have cancer, you may feel worried about different things in your life. This is normal. Someone from your medical team can sit and talk with you about these worries. They can help you get the information and support you need.

We are also here to talk and support you. There is more information on page 46 about our Support and Information Service. There is also a list of other useful organisations on page 48 of this booklet.

You might have worries about all or some of the following things:

How your body works or looks

Cancer and cancer treatments can affect how well your body works and sometimes, how you look. For example, problems sleeping, pain, hair loss or changes to how your body looks after surgery (see 'Body image' on page 30).

Day to day life

You might be worried about the impact on school or work, money, getting to and from appointments, or things like washing and dressing yourself.

Family and relationships

Being diagnosed with cancer will affect you and the people around you. You might have worries about your partner, children, parents, or friendships.

How you feel

Being told you have cancer will probably change how you feel. It is normal to have lots of different feelings and emotions like anger, frustration, loneliness, or fear. Some people find it helpful to share how they are feeling and get support on how to deal with their feelings.

Religious or spiritual

You may have worries about your faith and beliefs.

Lifestyle

Worries about your lifestyle might include how the cancer will affect your diet, the food you can eat and your hobbies. You might wonder about using complementary medicines such as aromatherapy and meditation.

Support

You may have worries about finding the right support or want to know what support there is. Such as joining support groups or being connected to other people with experience of primary bone cancer. See pages 46 and 48 of this booklet for how BCRT and other organisations can support you.

Whatever your worry, it is worth talking to your doctor or nurse about it. They are there to help you.

Holistic Needs Assessment

Some hospitals offer a ‘Holistic Needs Assessment’. This is where you have a chat with someone in your medical team who will ask you questions about your worries and concerns. It covers all parts of life, not just how the cancer and treatments affect the body.

Together, you will make a care and support plan to help you manage the worries and concerns. Ask your doctor or nurse for more information about this.

Body image

Cancer has changed my body

Cancer and cancer treatment can change your body. These changes in the way your body looks, feels and works can affect your 'body image'. This means the way you now see your body and feel about the way you look.

What are the common changes?

Changes in your body can be caused by cancer itself or by cancer treatments, such as surgery, chemotherapy (chemo) and radiotherapy. Some changes may be short-term, such as hair loss and others may be permanent. Common changes include:

- scars from surgery
- losing part of your body or part of an organ in your body
- loss of feeling (numbness)
- weight loss or weight gain
- hair loss
- lack of energy (fatigue)
- changes to how you feel about sex. This could be a loss of desire for sexual activity or changes that make sex difficult
- changes to your sex organs, like not being able to have a baby (infertility). Not all chemo medicines affect fertility. When they do, female patients may want to talk to their doctor about freezing eggs or ovarian tissue. Male patients may want to talk to their doctor about sperm banking

Talking to others is a great way of finding out how they dealt with things you might be going through

How will these changes affect how I feel about my body?

Skin problems or hair loss affect body image by changing the way you look. Changes like these may make you feel self-conscious. Changes that aren't easy to see, such as a hidden scar, can also affect the way you feel about yourself. Even if you don't look different to others, you may feel insecure about your body.

You may feel that others see you differently because you have cancer, even if you look the same. Not all changes are bad, though. Some people have positive changes in body image, such as realising the strength of their bodies.

Remember your personality isn't changed by cancer

How can I cope with how I feel about changes to my body?

The tips below can help you cope with body image worries. Remember that it's normal to feel anxious or worried about changes to your body. Give yourself time to get used to any changes and how you feel about them.

- Talk to others who are going through or have been through a similar thing. It'll help to hear how they coped with changes to their body.
- Be prepared for questions and comments about the way you look and practise with a friend how you'll respond.
- If people do comment, try not to take it too personally. Remember that people are not trying to hurt you. They may not know what to say.
- Even though your body may look and feel different, remember you are still the same person on the inside. Your personality, interests, and talents aren't changed by cancer.
- Try out new looks. Makeup, wigs, and headscarves could give you the extra confidence you need.
- Take care of your body with good food, lots of sleep and an exercise plan agreed with your doctor.
- If you can't do some of the activities or sports you used to, try to find a new activity that you'd enjoy. Learning a new skill can help you build confidence in yourself and your body.

For help coping with changes to your body:

Visit: changingfaces.org.uk
or call them on: 0300 012 0275

Visit: lookgoodfeelbetter.co.uk
or call them on: 01372 747 500

Call the Bone Cancer Research Trust's freephone Support & Information Line on: 0800 111 4855 (Monday to Friday, 9am to 5pm)

After treatment

What now?

The end of your treatment will come as a welcome relief, but it can also be a time of worry and anxiety. You may be worried about relapse or your cancer coming back. You may feel lost and alone or be worried about leaving behind the medical team and the support network at the hospital you have been used to. Your parents or carers may also feel like this. These are all normal feelings.

You may like to join a support group or contact other primary bone cancer patients through blogs or on social media.

Our team at the Bone Cancer Research Trust can put you in touch with other people who have experience of primary bone cancer.

Visit: bcrt.org.uk/support
Call us on: 0800 111 4855

Have a look at the list of other organisations that you might want to contact on page 48 of this booklet.

Follow-up care

When you finish treatment your doctors will want to keep an eye on you and you will be monitored for a long time. This is called 'follow-up care'.

Outpatient hospital visits will be needed on a regular basis. For example, every 2 to 4 months for the first 3 years after finishing treatment, every 6 months for the 4 to 5 years after that and then once a year.

These visits mean doctors can check your health and do some tests. These tests are very important because they can show up any 'late effects' from the cancer treatment and check if the cancer has come back (called 'relapse' or 'recurrence'). Follow-up care with an orthopaedic surgeon lets them look out for surgery related problems. They will also make sure the limb is working well.

These visits can also be useful to talk about any emotional or practical worries or problems you may have. If you have any problems in between these visits, get in touch with your doctor or clinical nurse specialist straight away.

Scanxiety

Scan anxiety or 'scanxiety', is the anxiety, worry or fear you might feel in the lead-up to a scan or to the scan results. These feelings and any others that might come up are normal.

During the time between your outpatient visits, you may feel unable to plan for the future; 1 year, or even 3 months ahead. It might help to have medium and long-term goals.

The best way forward is to plan ahead. Plan to get into college or university or work. You could even plan a trip for next year.

What if the osteosarcoma comes back?

Sadly, osteosarcoma can come back in some people. If the cancer does return, it may feel like the bottom has fallen out of your world, but there are treatments that you can be given.

You may be given a different mix of chemo medicines. The treatment may be more aggressive than before, meaning that higher doses are used. You may need more surgery, or if this isn't possible, maybe radiotherapy. Everyone is different and treatments will depend on each person.

The doctors and nurses will be able to talk you through the treatment options in detail.

Advanced osteosarcoma

Your doctor may have told you that your cancer can no longer be treated, and the focus now is to make you comfortable and give you as much time as possible with your loved ones.

You can find more information on this and coping with your emotions by contacting our Support and Information Team.

Visit: bcrt.org.uk/support
Call us on: 0800 111 4855

Try not to let the cancer rule your life. It might help to set medium and long term goals.

Asking the right questions

Being diagnosed with osteosarcoma can be a stressful and overwhelming time. It is often difficult to get all the information you feel you need from your medical team. You might leave an appointment with some unanswered questions.

Here is a list of some of the questions you may want to ask your medical team during your diagnosis, treatment, or after treatment.' Think of these as a starting point and don't be afraid to ask any other questions you have.

If you don't understand something, it's OK to ask your doctor or nurse to repeat themselves until you do. You could ask them to explain it in a different way.

Questions during diagnosis

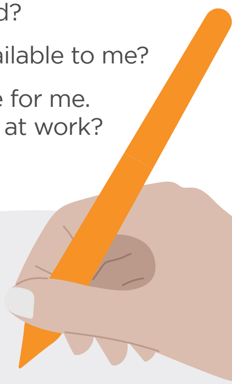
- Do you know the size of the tumour and where it is?
- How can I manage my symptoms?
- Will I need to make any changes to my day-to-day life, diet or exercise?
- Who can I contact if I have any more questions, and when?
- Who can I talk to if I am feeling overwhelmed?
- Has the cancer spread?
- How might the cancer and cancer treatments affect my fertility?
- What financial help is available

Questions during treatment

- What treatment will I have and how was this treatment plan decided?
- How long will the treatment last?
- How long will I have to stay in hospital?
- What are the side effects of the treatment and will I need medicines to control these?
- Am I at risk of any side effects later on in my life? Is there anything I can do to stop these from happening?
- Will the treatment affect my day-to-day life, such as going to work or school?
- What happens if the treatment doesn't work?
- Are there any clinical trials that I can take part in?

Questions after treatment

- Will I need rehab? How will it be arranged and where will it happen?
- Will I need follow-up tests to check the treatment has worked?
- What financial help is available to me?
- What support is available for me. For example at school or at work?



Handy tips

Note down any questions, worries or symptoms you have before your appointments. This will help you remember everything you want to talk about.

Ask a family member or friend to go with you. They could write down the answers to your questions, while you listen.

Make a note of the contact details of the medical team that you may want to speak to.

Glossary

You might hear a lot of medical words and terms that don't make sense at first when you talk about osteosarcoma. Here is a list of some of these words, with explanations about what they mean.

A

Anaemia: Lower than normal levels of red blood cells or haemoglobin in the blood.

Analgesic: Medicines that stop people feeling pain. Such as ibuprofen, paracetamol and codeine.

Antibiotics: Medicines that fight infections caused by bacteria.

Antiemetics: Medicines that stop people from feeling sick (nausea) or being sick (vomiting).

Autograft: Replaces tissue from a part of the body using tissue from another part of the same person's body.

B

Benign: A mass of cells that is not cancerous. These tumours grow in one place and do not spread to other tissues or organs.

Biopsy: A small sample of a tumour that is taken. A doctor called a 'pathologist' will look at the cells or tissue from the sample under a microscope. They will do tests on it.

Bone sarcoma: The name given to cancer that starts in the bone. It is also called primary bone cancer.

C

Cells: The building blocks of the body. Cells are very, very small and can only be seen under a microscope. All living things are made up of cells.

Central Line: Long, flexible, plastic tubes that go into a 'central' blood vessel in the chest near the heart. These are used to give chemotherapy medicines.

Chemotherapy (chemo): A treatment for cancer that uses one or more medicines to destroy cancer cells.

Cisplatin: A chemotherapy medicine used to treat osteosarcoma. It works by sticking to DNA and starting a process called 'apoptosis' which destroys cancer cells.

Clinical trial: Used to test how well new medicines or treatments work in people.

Counsellor: A person who provides counselling, a type of talking therapy that allows a person to talk about their problems and feelings in confidence.

CRP (C-Reactive Protein): Blood tests to check the levels of CRP are done to look for signs of inflammation (swelling) and infection.

Curettage: A type of surgery which removes the tumour by scraping or scooping the cancer cells away.

Cyclophosphamide: A chemotherapy medicine used to treat primary bone cancer. It belongs to a group of medicines called 'alkylating agents'. Cyclophosphamide slows the growth of cancer cells by affecting how the DNA works.

Cytotoxic: Toxic to cells. A cytotoxic medicine destroys cancer cells.

D

Dexamethasone: A steroid medicine. Dexamethasone is a type of medicine called a 'corticosteroid'. It is used to help stop inflammation (swelling). It may be used to treat some of the side effects caused by chemotherapy.

Diclofenac: A medicine that stops people feeling pain. It may be used after an operation. Diclofenac belongs to a group of medicines called 'non-steroidal anti-inflammatory medicines' (NSAIDs).

Distal: Far away from where it is attached. For example, the thigh bone (femur) is attached to the hip, so the distal part of the femur is the part of the bone furthest from the hip (nearest to the knee joint).

DNA (deoxyribonucleic acid): A long molecule (as long as 2 metres) found in the middle of each cell. DNA is the genetic material of a cell. It contains genes or 'instructions' that are passed on from one cell to the next when they grow and divide.

Docetaxel: A chemotherapy medicine sometimes used to treat osteosarcoma. It is given straight into a vein by infusion. It works by affecting the cancer cells when they are trying to grow and divide.

Doxorubicin: A chemotherapy medicine used to treat osteosarcoma. Doxorubicin is a red liquid that is given into a vein by infusion. It is a type of medicine called an 'anti-tumour antibiotic'. It affects the cancer cell's DNA when it is getting ready to divide.

E

Electrocardiogram (ECG): A test that checks the electrical activity of the heart. It is usually done before and during treatment to see how well the heart is working. It can detect any damage to the heart at an early stage.

Echocardiogram (Echo): A test used to check how well the heart is working.

Enneking System: A system doctors use to stage musculo-skeletal tumours.

Etoposide: A chemotherapy medicine used to treat osteosarcoma. It can be given into a vein by infusion or as a capsule to swallow. It stops the DNA in a cancer cell from fixing itself, destroying the cell.

F

FBC (Full Blood Count): A blood test that gives information about blood cells and how many cells there are. It looks at red blood cells, white blood cells, platelets and levels 'haemoglobin', which carries oxygen in the blood.

Febrile Neutropenia: Fever (high temperature) in a person that has neutropenia. This is where the number of white blood cells called 'neutrophils' is too low. The fever may be a sign of infection.

Femur (thigh bone): The longest bone in the body.

G

Gene: Found inside each cell. A gene is a set of instructions that tell the cell what type of cell it is, when to divide and when to die. Genes are made up of DNA.

Gemcitabine: A chemotherapy medicine sometimes used to treat osteosarcoma. It is given straight into a vein by infusion. It works by affecting the DNA within the cancer cells.

Glomerular filtration rate (GFR): A measure of how well a person's kidneys are working.

Grade: How active the cancer is. Tumours are graded by doctors called 'pathologists' who look at tumour samples under a microscope. One of the things they look at is how many dividing cells they can see. High grade tumours are often more aggressive.

H

Hickman Line: A type of central line used to give fluids, nutrition, chemotherapy and other medicines directly into the blood. It can also be used to take blood samples.

High-Dose Chemotherapy: Intensive cancer treatment using very high doses of chemotherapy medicines to destroy cancer cells.

I

Ifosfamide: A chemotherapy medicine sometimes used to treat osteosarcoma. It works by damaging DNA in the cancer cell so it cannot copy itself. This makes it difficult for the cell to divide.

Infusion (drip): A way of giving a set amount (dose) of intravenous (I.V.) medicines such as chemotherapy or painkillers, over a set period of time.

Investigations: Tests done by doctors to help diagnose and monitor an illness.

Intravenous (I.V.): Giving medicines or fluids directly into the blood.

L

Lactulose: A medicine used to treat constipation (problems with bowel movements). Lactulose is a type of medicine called a 'laxative'.

Late Effects: Problems that people can have after cancer treatments have finished, sometimes months or years later.

LFTs (Liver Function Tests): Tests, such as a blood sample, to check how well the liver is working.

Limb-Sparing Surgery (Limb Salvage Surgery): Surgery to remove a tumour from an arm or leg (limb). It is used instead of amputation where possible and aims to allow the limb to work well after surgery.

Local Treatment: A treatment that targets a specific area of the body. Surgery and radiotherapy are local treatments.

M

MAP: The current standard chemotherapy treatment for osteosarcoma. MAP is 3 medicines used together. They are called ‘methotrexate’, ‘doxorubicin’ and ‘cisplatin’.

Malignant: A ‘lump’ or ‘growth’ of tissue made up of cancer cells, that keep dividing. The cells are able to move in the blood or lymphatic system to other parts of the body where they can form a new growth.

Mesna: A medicine given with chemotherapy. It helps reduce problems in the bladder, which may be caused by ‘ifosfamide’ and ‘cyclophosphamide’.

Metastasis: The process of cancer cells moving from the original (primary) site, to other parts of the body. This means the cancer has spread.

Methotrexate: A chemotherapy medicine used to treat osteosarcoma. It works by slowing the growth of the cancer cells.

Metoclopramide (Maxolon): A medicine used to treat nausea and vomiting.

Mifamurtide (Mepact): A medicine used to treat osteosarcoma in some people. It is given with chemotherapy, after surgery. It helps white blood cells in the body attack any cancer cells that may be left.

Morphine Sulphate: A medicine used to treat severe pain. It belongs to a group of medicines called ‘opioids’. Morphine Sulphate can be taken as a tablet or a syrup.

Multi-disciplinary team (MDT): A team made up of people who are experts in different areas of medicine. They work together following national guidelines to work out patient treatment plans, decide on further tests and referrals, and keep records.

Multi-focal: When osteosarcoma starts in more than one bone at the same time.

N

Nasogastric Tube (NG Tube): A thin, flexible tube that is put into the nose and fed down the back of the throat into the stomach. It can be used in 2 ways: to give nutrition or medicines and to remove the contents of the stomach, including air.

Neoplasm: Another name for a tumour. The word neoplasm means ‘new growth’. Neoplasms are either benign (not cancer), or malignant (cancer).

Neutropenia: A low level of neutrophils (a type of white blood cell). Chemotherapy can cause neutropenia. A person with neutropenia may not be able to fight off infections very well. Antibiotics may be given to someone with neutropenia.

Neutrophils (‘Neuts’): The most common type of white blood cell. They help to fight off disease and infection. Neutrophils are a type of cell called a ‘phagocyte’ which means they ‘eat’ bacterial cells.

O

Occupational Therapist: A person who helps people who have been ill or had surgery, to adapt to changes caused by their illness. This might mean helping them to get around in day-to-day life or go back to work or school.

Oncologist: A doctor who treats and looks after people with cancer.

Ondansetron: A medicine used to treat or stop nausea and vomiting caused by cancer treatments and surgery.

Orthopaedic Surgeon: A surgeon who treats an illness using surgery that affect the bones, joints, muscles, ligaments, tendons and nerves.

Osteosarcoma: A rare cancer that can start in the bones and in very rare cases, in soft tissue, like the muscles. Osteosarcoma is the most common type of primary bone cancer in children and young people.

P

Paediatrician: A doctor who is specially trained in treating children.

Palliative: Medicine and treatment that help to support people and manage and relieve their symptoms, to improve their quality of life.

Pathologist: A doctor who does tests in a lab to help diagnose disease. They look closely at blood and tissue samples.

PEG (Percutaneous Endoscopic Gastrostomy): Used to help keep a person's weight stable if they cannot eat or swallow. A PEG is used to get nutrients and fluids directly into the stomach.

Physiotherapist (Physio): Someone who helps with rehabilitation after surgery. For example, helping a person to strengthen their muscles or to walk.

PICC (Peripherally Inserted Central Catheter): A long, thin tube that is put into a vein in the arm, usually near the elbow. It is fed through the vein until the end reaches a vein near the heart.

Primary bone cancer: The name given to cancer that starts in the bone.

Portacath® (Implantable port): Made up of a thin tube (catheter) and a 'port' or 'chamber'. The tube is implanted under the skin in the chest and sits in a vein near to the heart. The port is attached to the end of the tube and sits just under the skin. The port contains a thin rubber disc through which special needles can be attached to give chemotherapy and other I.V. treatments, fluids and to take blood samples.

Prednisolone: A type of medicine called a 'corticosteroid'. It is used to reduce inflammation (swelling). Prednisolone may be used to treat some types of cancer, infections and side effects caused by chemotherapy.

Prognosis: A doctor's prediction of how a disease will affect a person.

Promethazine: An 'anti-histamine' medicine. Promethazine can be used to treat allergic reactions and help with sleep problems. It can also make someone calm and sleepy before surgery.

Prophylactic: A medicine or treatment used to stop a disease or infection from happening. For example, 'prophylactic antibiotics' may be given after surgery to stop a wound getting infected.

Prosthesis: A device designed to replace a missing part of the body. For an example, an artificial limb.

Prosthetist: A doctor who looks after anyone who needs an artificial limb. They can help to find the best prosthesis and give advice on rehabilitation.

Proton Beam Therapy (PBT): A type of radiotherapy that delivers high-dose radiation to the tumour. This means healthy tissue close to the tumour is not affected by the radiotherapy.

Proximal: Near to where it is attached. For example the thigh bone (femur) is attached to the hip, (its point of origin) so the proximal femur is the part of the bone 'nearest' to the hip.

R

Radiotherapy: Treats tumours using high doses of concentrated radiation.

Randomised Clinical Trial: To reduce any chance of bias, people are put into random groups when taking part in a clinical trial. This might be done by a computer.

Recurrent Cancer: Cancer that has come back when a person is in remission. It might come back to the original (primary) site or to another part of the body.

Relapsed Cancer: Cancer that comes back shortly after treatment has ended. It might come back to the original (primary) site or to another part of the body.

Red Blood Cells: Cells in the blood that carry oxygen to all parts of the body.

Regimen: A plan of the medicines and treatments a person may have. It lets all the carers know exactly how the person will be treated. It will say the sort of treatment, the dose, how often and how long it will be given for.

Rehabilitation (Rehab): A type of treatment that helps people do the things they did before they got ill. Such as walking after surgery. Physiotherapists and Occupational Therapists are specially trained in rehabilitation.

Remission: When the signs and symptoms of cancer have reduced. Remission can be ‘partial’ or ‘complete’. In a complete remission, all signs and symptoms of cancer have gone. If you remain in complete remission for 5 years or more, some doctors may say that you are cured.

Resection: Using surgery to remove tissue, bone or an organ from the body.

S

Second Opinion: Getting the view of a doctor who has not yet been involved in a person’s case. A GP usually asks for a second opinion.

Side Effects: When medicines that people are given to treat a disease also affect parts of the body that are healthy. Side effects are usually unwanted.

Stage: The stage of a cancer describes its size and if it has spread to other parts of the body.

Steroids: Medicines such as ‘corticosteroids’ and ‘glucocorticoids’. Steroids are similar to hormones that are made by the body when it is stressed, ill or injured. They reduce inflammation (swelling). They are used to treat some types of infection, cancer and side effects.

Systemic treatment: A treatment that can affect the whole body. Chemotherapy is a ‘systemic’ treatment, as it treats the whole body.

T

Tissue: A group of cells that work together to do a certain job in the body.

Total Parenteral Nutrition (TPN) / Parenteral Nutrition (PN): When a person is given nutrients directly into their blood through a drip.

Treatment Cycle: A cycle includes the treatment time, which could be 3 to 4 days, plus a rest period for the healthy cells of the body to recover.

U

Us & Es (Urea and Electrolytes): A type of blood test to check the levels of salts, urea and creatinine. It is used to check how well a person's kidneys are working.

V

Venflon (Cannula): A small, flexible plastic tube that is put through the skin into a vein by a needle which is attached to it. The needle is removed when the tube is inside the vein. Venflons are used to give medicines, fluids, and blood products into the blood intravenously (by I.V.).

W

White Blood Cells: Cells that are part of the immune system. They help the body to fight off infections and disease.

If you think there is a word missing from our glossary, please let us know. Email our team at: support@bcrt.org.uk
or call 0800 111 4855

A little more about us

The Bone Cancer Research Trust

We are the Bone Cancer Research Trust (BCRT), a charity devoted to fighting primary bone cancer (PBC).

Our mission is to save lives and improve outcomes for people affected by PBC. We do this through:

- Research
- Information
- Awareness
- Support

Our ambition is for a future where PBC is cured. For those affected by it right now, our high-quality information and supportive network means no one should have to feel alone.

How the Bone Cancer Research Trust produce information and the PIF TICK

This booklet has been created by BCRT. We provide lots of up-to-date information for patients and families, that you can trust.

In January 2024, BCRT was re-awarded PIF TICK certification. It is the UK-wide quality mark for health information. If the PIF TICK is shown on our booklets, leaflets and webpages, this means the health information has been through a professional and robust production process.

You can be confident that the information in this booklet is trustworthy because it meets PIF's 10 criteria:

1. Information is created using a consistent and documented process.
2. Staff are trained and supported to produce high-quality information.
3. Information meets an identified consumer need.
4. Information is based on reliable, up-to-date evidence.
5. Patients are involved in the development of health information.
6. Information is written in plain English.
7. Print and digital information is easy to use and navigate.
8. Users can give feedback on information.
9. Information is promoted to make sure it reaches those who need it.
10. The impact of information is measured.

You can find out more information on PIF's website: **piftick.org.uk**

Our Support and Information Service

We're here for anyone who needs information on, or support with, primary bone cancer.

We can provide you with an added layer of support on top of that given by healthcare professionals, who we work together with.

We provide:

- A freephone Support and Information Line - **0800 111 4855.** Open Monday to Friday, 9am to 5pm.
- A website with information about primary bone cancer and our services: **bcrt.org.uk**
- Facebook support groups (also called our 'Digital Support Groups').
- Virtual primary bone cancer and tumour support group meetings.
- A Bone Cancer Conference, bringing together our community in a supportive and safe environment. This will be held either on an annual basis or twice yearly.
- Financial Assistance Grants for every new patient in the UK.
- Confidential and professional support from our dedicated team.
- Access to patient stories and the opportunity to get in touch with others, who have had similar experiences.
- Access to reliable and accurate information about bone cancer.
- A library of Support and Information videos, covering topics about primary bone cancer.
- Details of other organisations that can provide help and support.

Get in touch

If you would like more information or have any questions about osteosarcoma, contact our Support and Information Team. They have a list of references that were used to create this booklet. They can also provide you with a shorter leaflet about osteosarcoma.

Call: 0800 111 4855
Email: support@bcrt.org.uk
Visit our website: bcrt.org.uk

@BCRT
/BoneCancerResearchTrust
@bonecancerresearch

Useful organisations

The cancer charities and useful organisations listed in this section can give you more support and advice. If you can't find what you're looking for, contact the Bone Cancer Research Trust's Support and Information Team (see page 46).

Changing Faces

Guidance and support for anyone who may have a scar, mark or condition on their face or body.

Website: changingfaces.org.uk

Call: 0300 012 0275

Children's Cancer and Leukaemia Group (CCLG)

Lots of really helpful information for young people with cancer and their families.

Website: cclg.org.uk

Call: 0333 050 7654

Citizens Advice Bureau

Advice on legal, employment, money issues and lots more.

Website: citizensadvice.org.uk

Call in England: 0800 144 8848

Call in Wales: 0800 702 2020

Department for Work and Pensions

For advice on benefits you or your parents may be entitled to.

Website: dwp.gov.uk

The George Pantziarka TP53 Trust

Support for people affected by Li-Fraumeni Syndrome and related conditions.

Website: tp53.org.uk

The Little Princess Trust

Visit the Little Princess Trust to find out how you can access a free wig.

Website: littleprincesses.org.uk

Call: 01432 760 060

Look Good Feel Better

Wellbeing workshops and classes for people living with cancer.

Website: lookgoodfeelbetter.co.uk

Call: 01372 747 500

Macmillan Cancer Support

Provide a wide range of information for all ages as well as practical and financial support.

Website: macmillan.org.uk

Call: 0808 808 0000

Maggie's

Information and support for people with cancer and their families. Maggie's has support centres across the UK that offer a calming space to meet and chat.

Website: maggies.org

Call: 0300 123 1801

Move against cancer

Work to support and inspire people with cancer and their families.

Website: movecharity.org

Samaritans

Provide emotional support to anyone who is feeling distressed, struggling to cope, or having suicidal thoughts or feelings. They can also help if you are worried about how another person is feeling

Website: samaritans.org

Call free on: 116 123

Skeletal Cancer Trust

Offer knowledge and advice on the best technology available in the manufacture of artificial limbs, special crutches or wheelchairs.

Website: skeletalcancertrust.org

Teenage Cancer Trust

Care, support and information for young people with cancer.

Website: teenagecancertrust.org

Call: 0207 612 0370

Teens Unite

Social, emotional and physical support for people aged 13 to 24 diagnosed with cancer.

Website: teensunite.org

Call: 0199 244 0091

Trekstock

Lots of information and support for people in their 20s and 30s who are living with cancer.

Website: trekstock.com

Call: 0204 454 17601

Young Lives vs Cancer

Lots of Information and support for children and young people with cancer.

Website: younglivesvscancer.org.uk

Call: 0300 303 5220

Thank you

We would like to say thank you to everyone who has helped review Version 4 of this booklet.

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