Your guide to

EWING SARCOMA

Trusted Information Creator

Patient Information Forum



BONE CANCER RESEARCH TRUST

Just diagnosed with Ewing sarcoma?

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 old 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. Ewing sarcoma is one of these.

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

- what Ewing sarcoma is
- what treatments you may have and how they may affect you
- ways to help you manage side effects
- how you may feel
- what happens after your treatment

You might be older or younger than 16 to 24 years old and still find this booklet useful.

The Glossary on pages 38 to 44 explains medical words and terms relating to Ewing sarcoma 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 Ewing sarcoma 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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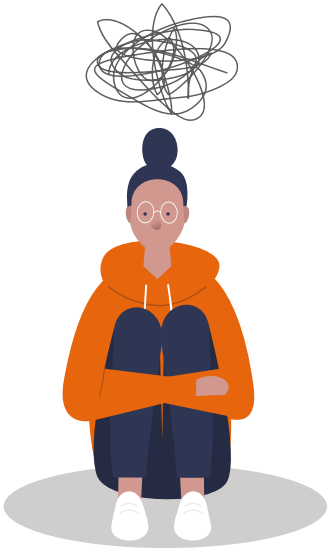
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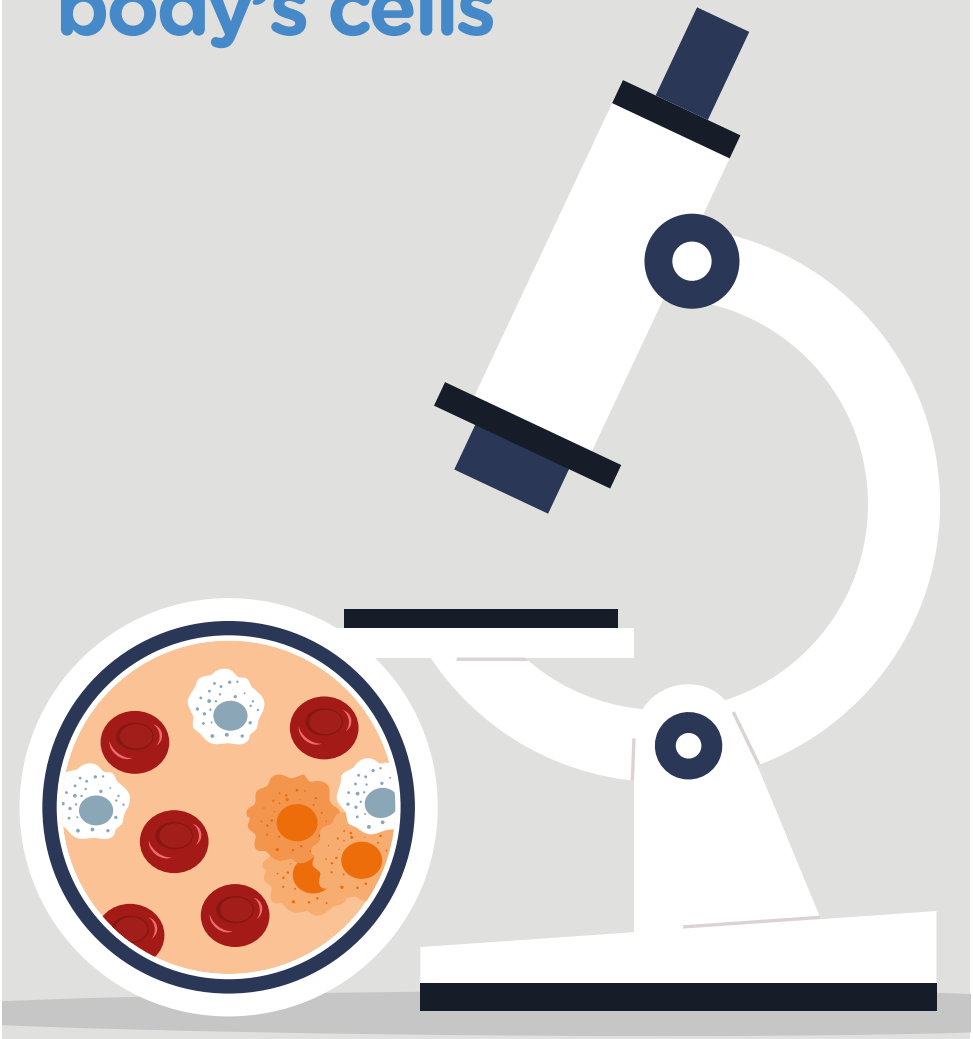
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Hearing that you have cancer is scary and there will be lots to take in. This booklet is here to help you, as and when you need it.



Cancer is a disease of the body's cells



Cells and cancer

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'.

Your genes are passed to you (inherited) from your parents. This is why you may have similar hair and eye colour to them, for example.

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 condition '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.

There are over 200 types of cancer that affect different organs and tissues.

Primary bone cancer

About primary bone cancer

Primary bone cancers, also known as 'bone sarcomas', are rare types of cancer.

- The average number of primary bone cancer cases diagnosed in the UK each year is around 650. This is based on data from 2019, 2021 and 2022 (cases recorded during 2020 have not been included due to a drop in the numbers registered due to covid).
- Approximately 130 of the 650 cases of primary bone cancer diagnosed each year are Ewing sarcoma.
- 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 Ewing sarcoma.

The picture on page 7 shows the different parts of a bone.

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

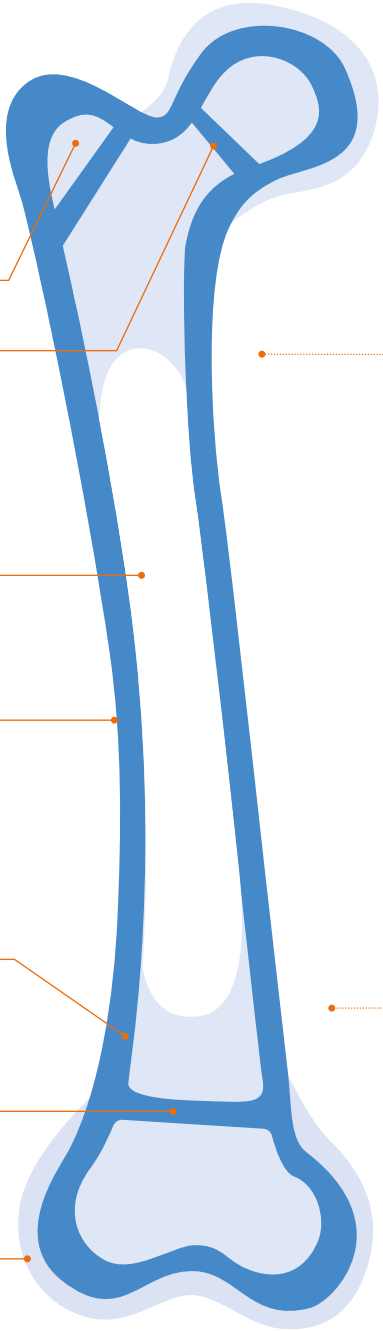
Bones:

- 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



Apophysis

Physis (also called the growth plate)
This is where the bone grows longer

Medullary Cavity

Periosteum
Protective layer where ligaments and tendons join to bone

Cancellous Bone
Spongy Bone

Physis (also called the growth plate)
This is where the bone grows longer

Cartilage
Stops bone to bone contact at joints

Diaphysis (also called the shaft)
Ewing sarcomas often start in the diaphysis

Ewing sarcoma

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

Yes, there are 7 different types of primary bone cancer.

There are 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 Ewing sarcoma. What is it?

Ewing sarcoma is a rare cancer that can start in the bones or in soft tissue like the muscles. It belongs to a group of tumours called 'undifferentiated small round cell sarcomas of the bone and soft tissue'. Ewing sarcoma tumours are likely to grow and spread quickly.

Ewing sarcoma is the second most common type of primary bone cancer found in young people.

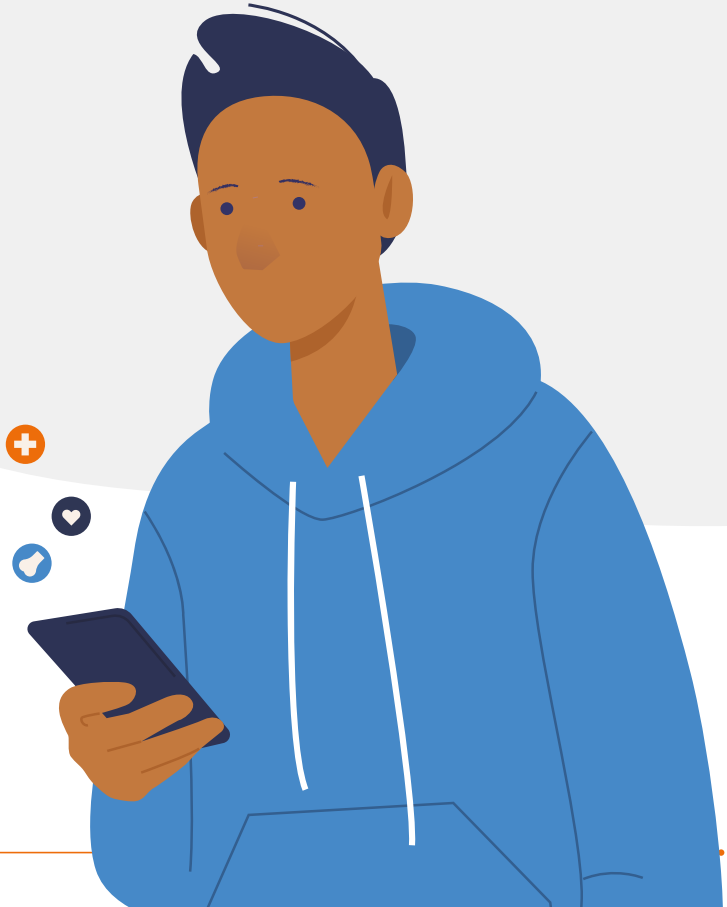
Many cases of Ewing sarcoma are found in people between the ages of 10 to 24 years. However, Ewing sarcoma can also affect older adults.

- Each year in the UK around 130 people are diagnosed with Ewing sarcoma.
- Most people are under 30 years old when they are diagnosed with Ewing sarcoma.
- The average age of people with Ewing sarcoma is 15 years old.

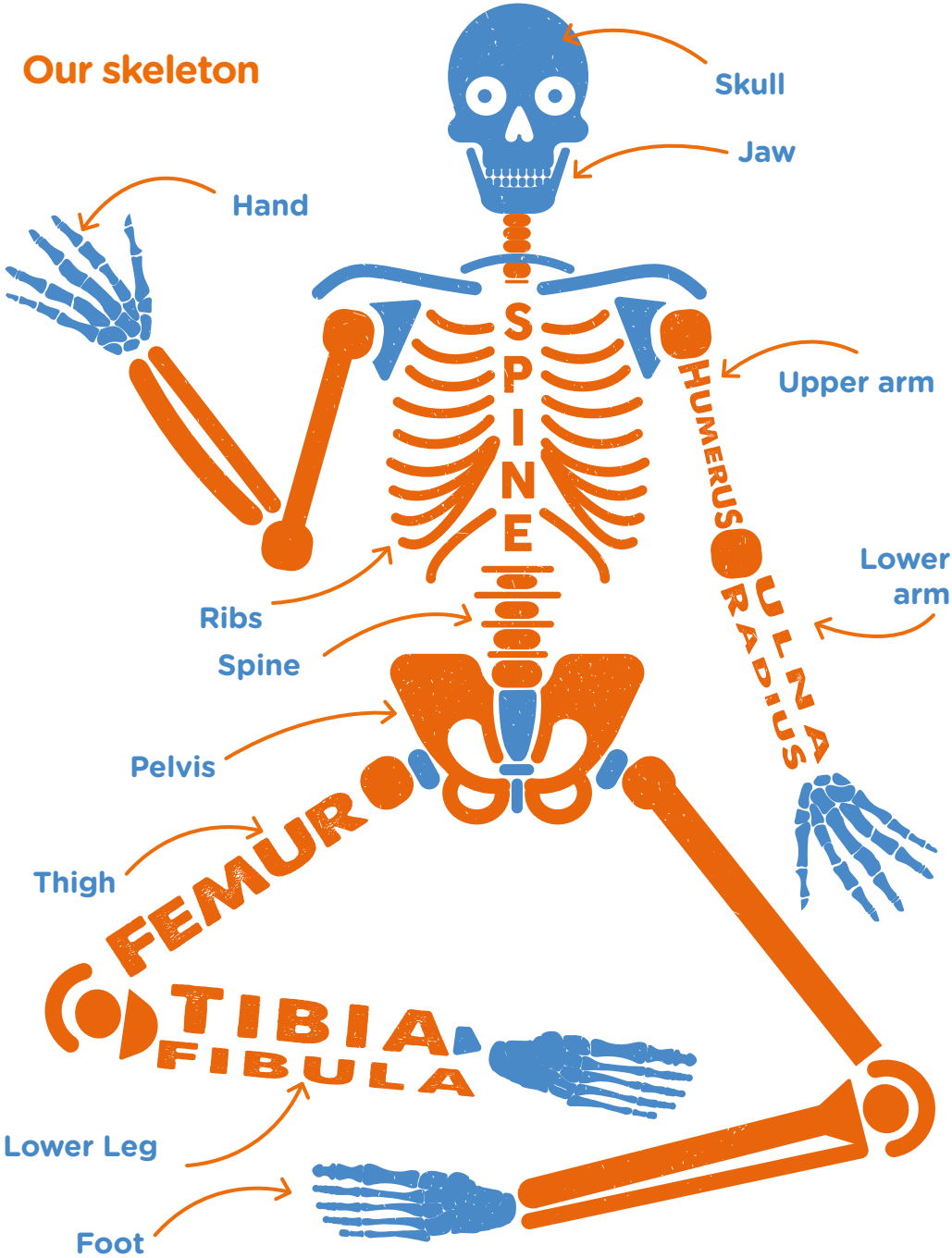
Did you know?

Ewing sarcoma is named after Dr James Ewing. He first identified the cancer in 1921.

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



Our skeleton



What parts of the body can Ewing sarcoma affect?

Ewing sarcoma can start in any bone or soft tissue of the body. It is most common in bones. The most common places it may start are the pelvis, ribs, spine, and the long bones of the arms and legs. These are shown in orange on the skeleton picture. The other labelled parts of the body show the less common places Ewing sarcoma may start.

Is everybody's Ewing sarcoma the same?

Ewing sarcoma belongs to a group of cancers called 'undifferentiated small round cell sarcomas of the bone and soft tissue'. Ewing sarcoma happens when 2 separate genes (DNA) combine to become a 'hybrid' gene. This is called a 'fusion'. Most Ewing sarcomas are caused by fusions between the same 2 genes.

A very small number of people have small round cell sarcomas of the bone and soft tissue, which are similar to Ewing sarcoma, but have a fusion between different genes. These are called 'Ewing-like tumours'. Symptoms and treatments for Ewing sarcoma and Ewing-like tumours are currently the same.

How did I get Ewing sarcoma?

Doctors do not yet know what causes fusion between certain genes, or how to stop it happening.

We do know that:

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

Ewing sarcoma tends to be more common in White people than in Black, Asian, Hispanic and African people.

Diagnosis

How will Ewing sarcoma 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 Ewing sarcoma. The main ones are:

- 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 Ewing sarcoma is at the original site (primary site), or has spread (is metastatic)
- how the tumour responds to treatment

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

How will my Ewing sarcoma be treated?

If doctors think you may have bone cancer, the type of treatment you will have, will depend on 2 questions:

- what is it?
- where is it?

What is it?

X-rays and scans may show that you are very likely to have Ewing sarcoma. 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 Ewing sarcoma.

Where is it?

X-rays and scans also help doctors to see the size of the tumour and exactly where in the body it is. The scans also check if the cancer has spread to any other parts of the body. This is known as 'staging' of the cancer.

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

Ewing sarcoma 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 metastases'. In rare cases, Ewing sarcoma spreads to other bones or bone marrow.

Treatment

Where will I be treated?

Where you are treated will depend on where the cancer is 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. You will probably go to Oswestry or Birmingham.
- In Scotland, there are 3 bone cancer centres: Glasgow, Edinburgh and Aberdeen.
- In Northern Ireland, there is a bone cancer centre in Belfast.

The bone cancer centres are shown on the map on page 14. You may have to travel a long way to get to a bone cancer centre.

Other treatments for Ewing sarcoma, such as chemotherapy and radiotherapy can take place at different hospitals around the UK. Your MDT will decide where you will have your chemotherapy and radiotherapy.

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

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.

The MDT will plan and decide on what treatment and care is best for you. They will include you in the decision making.

Your Ewing sarcoma may also be discussed by the National Ewing sarcoma MDT. But your treatment will be managed by your MDT.

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

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.

Will I need any tests before treatment?

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 Ewing sarcoma can affect these organs. Doctors need to know how well they are working before treatment starts.

Types of treatment

There are different treatments for Ewing sarcoma. Some are called 'local' and some are called 'systemic'.

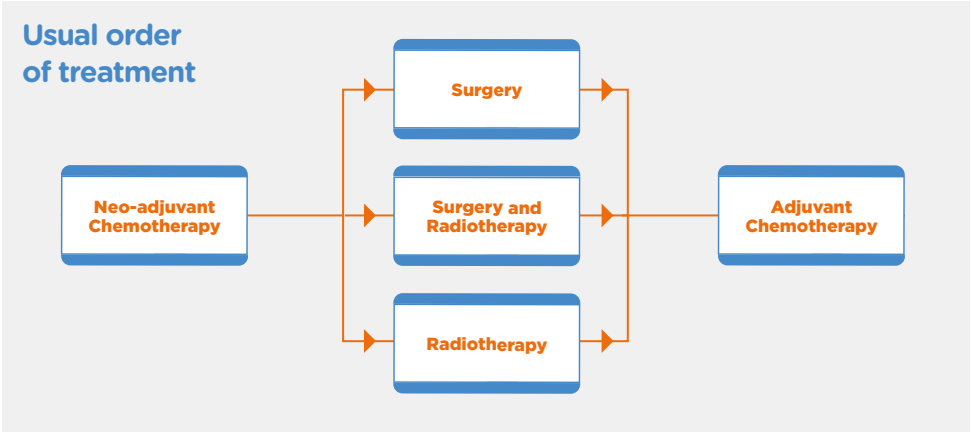
- Local treatment includes surgery and, or radiotherapy. The local treatment chosen will depend on whether the tumour can be removed by surgery.
- Systemic treatment includes chemotherapy, before and after surgery.

The type and order of treatment you have may be different to someone else with Ewing sarcoma. This is because the treatment options depend on a number of things like where in your body the tumour is.

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.

Ask your doctor any questions you have about your treatment plan, before treatment starts.

The image below shows the usual order of treatment for Ewing sarcoma. You may have all, or only some of the treatments shown. Keep reading to learn more about each treatment.



Chemotherapy

Chemotherapy, sometimes called chemo, is a systemic treatment. It travels around the whole body in the bloodstream. In the UK and most other countries, chemo for Ewing sarcoma is given both before and after surgery.

The standard chemo given to treat Ewing sarcoma before and after surgery is internationally recognised as the VDC/IE arm from the Euro Ewing 2012 trial (EE2012). The medicines given are called Vincristine, Doxorubicin, Cyclophosphamide, Ifosfamide and Etoposide.

You will be given more than one medicine at the same time. This means that if one doesn't work very well, the others may still destroy the cancer cells.

Chemo given before surgery is called 'neo-adjuvant chemotherapy'. It usually lasts for 14 cycles and is given every 2 weeks. Your chemo will probably start soon after you have been told you have Ewing sarcoma.

The aim of chemo before surgery is to:

- shrink the tumour
- destroy any cancer cells that could have spread from the original site (primary site) to other areas of the body

Most people will have more chemo after the tumour is removed by surgery, or following radiotherapy. This is called 'adjuvant chemotherapy'. The aim of chemo after surgery is to destroy any remaining cancer cells and lower the chance of the cancer coming back. Your doctor will talk to you about how many cycles of chemo may be needed. It usually lasts around 10 weeks.

How will I be given chemo?

For Ewing sarcoma, 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, near the heart.

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 goes straight into a vein via a long tube. The tube is connected to a bag that holds the chemo medicine. 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 are the cancer cells?

Cancer cells divide and grow quickly, so chemo medicines were developed 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. However, healthy cells usually repair themselves, unlike cancer cells.

You can find out more about the side effects of chemotherapy and other Ewing sarcoma treatments on page 21.

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



Radiotherapy

Radiotherapy is a type of 'local' treatment. It treats the tumour with high doses of concentrated radiation.

Radiotherapy may be used:

- before surgery to shrink the cancer
- after surgery to destroy any cancer cells that remain in the area
- instead of surgery if the tumour cannot be removed by surgery
- if there is a risk that surgery would limit how well your body works

If radiotherapy is given after surgery this may be because:

- not all the tumour could be completely removed during surgery
- some of the tumour is still active when looked at under a microscope

Radiotherapy is usually given as a single dose each day for about 5 to 6 weeks. It should only take a few minutes to have the dose. Chemo will usually continue during radiotherapy treatment.

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 certain people will be eligible for PBT. Your doctor will talk to you if they feel PBT will benefit you and your case would be reviewed by an expert panel. In the UK, PBT is only available at The Christie Hospital, Manchester and at University College London Hospital, London.

Surgery

Surgery is a type of 'local' treatment. Most people with Ewing sarcoma will have surgery to remove the primary tumour. Surgery usually happens after cycle 9 of chemotherapy. Your medical team will talk to you about when surgery will happen. It may depend on whether you also need radiotherapy.

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. For example, if it is in the pelvis or spine. In this case, radiotherapy may be used instead. You can read more about radiotherapy on page 18.

If your Ewing sarcoma 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 the whole or part of the limb. This is called an 'amputation'. You can read more about this on page 20.

If the tumour has spread to other parts of the body, your doctor and surgeon may 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's worrying you or there's something you don't fully understand, just ask.

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

If the tumour is in your arm or leg, you may have limb-sparing surgery.

This is where the whole tumour is removed. 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 of the bone is replaced with a metal implant called an 'endoprosthesis'. 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 have regular check-ups with your surgeon. They will check how you are recovering and if the implant or bone graft is working well and not damaged. 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 MDT will decide if an amputation is the best treatment for you. Your surgeon will talk to you about this.

What happens after the amputation?

After the amputation you will need to wait for your stump (the part of your limb 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 your 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.

Visit our website to find out more about amputation: **bcrt.org.uk/amputation**

Side effects

Some treatments for Ewing sarcoma, like chemotherapy and radiotherapy can cause side effects. Most side effects go away after treatment has finished. The most common side effects are listed below, along with tips for managing these.

When doctors tell you the list of side effects that you could get, 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 isn't working. Everyone is different.

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

Feeling and being sick

The doctors can give you anti-sickness tablets to help you stop 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 may 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 to see the oncologist. You will be given antibiotics to fight off an infection if you are found to 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 to reduce the feeling of 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 suddenly 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 important to eat a healthy diet. Eating a variety of foods means you get all of the energy, vitamins and minerals you need. This will help your body and keep your immune system working well.

CCLG (The Children & Young People's Cancer Association) have a booklet called 'Helping your child to eat well during cancer treatment'.

You can find it on their website: **cclg.org.uk/publications** or call them on: **0333 050 7654.**

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

Cancer treatment and fertility

Some cancer treatments, such as chemotherapy medicines and radiotherapy, can affect fertility (the ability to have children). The effect on your fertility will often not be known until much later after treatment has finished.

Before treatment starts, your doctor should talk to you about how the treatments may affect your fertility. It may seem like an odd thing to think about right now, but there are ways to preserve fertility. Freezing your eggs or ovarian tissue or storing sperm (called 'sperm banking') before treatment, gives you the option to have children in the future.

Macmillan Cancer Support have more information and advice on cancer treatments and fertility.

Visit their website:
macmillan.org.uk
or call them on:
0808 808 0000

Stem cell transplant

What is a stem cell transplant?

Sometimes, part of the treatment for Ewing sarcoma involves a procedure called a 'stem cell transplant'. This is to help replace blood cells that have been destroyed by chemotherapy (chemo). Your medical team will talk to you about whether you can have a stem cell transplant.

Bone marrow stem cells can divide and develop into many different types of cells, including blood cells. If you need a stem cell transplant, your stem cells will be collected from your blood before the high-dose chemo starts.

This collection is called 'stem cell harvesting'. The stem cells are then transplanted back into you after the high-dose chemo. These stem cells help replace blood cells that have been destroyed by the chemo.

How are the stem cells collected?

Before the stem cells can be collected, you will be given a special hormone called G-CSF. This increases the number of stem cells your bone marrow makes, and releases them into your blood. You will have regular blood tests to count the number of white blood cells ('neutrophils') in the blood. An increase in the number of white cells is a sign that the stem cells have moved from the bone marrow into the blood.

On the day of the stem cell harvest you will have a blood test to measure the number of stem cells in the blood. The harvesting of the cells will take place using a special machine. This usually happens at outpatients or day care. The harvested stem cells are stored and frozen until they need to be put back into your blood.

How are the stem cells put back into my blood?

The stem cells are put back into your blood by drip (infusion). It can take a few weeks for the bone marrow to fully recover and start making new blood cells. During this time, you may not be able to make white blood cells (neutrophils). This means you may be at a higher risk of infection. Because of this, you may be given antibiotics.

You may also have to stay in isolation during this time. This means staying away from other people so they can't pass on their germs. It's a good idea to pack some things to do during this time, like books and games.

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 of 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 Ewing sarcoma. They are important in developing new treatments or improving tests to diagnose Ewing sarcoma.

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 studies 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. 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 would encourage you to take a look at the information we provide on our website (see page 27).

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. You may be able to get a travel assistance grant from us, to help with travel costs. Visit our website to find out more about this: **bcrt.org.uk/support**

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 may also mean 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 taking part in a trial.

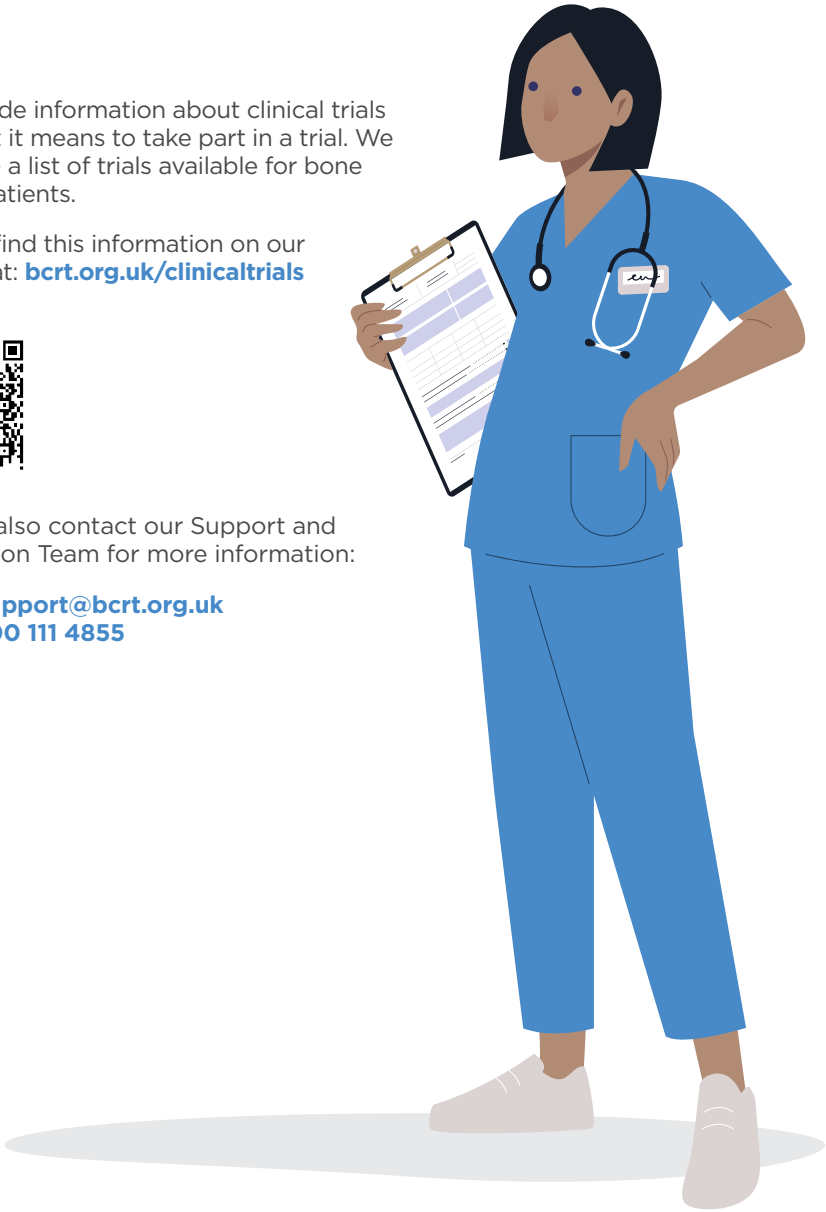
You can leave a clinical trial at any point. This will not affect the care and further treatment you have.

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. You may have worries about this. 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 such as 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 manage 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 and 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 about what support there is, such as joining support groups or being connected to others with experience of primary bone cancer.

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.

Macmillan Cancer Support provide more information on what a Holistic Needs Assessment involves and why it is helpful.

Visit their website: macmillan.org.uk
or call them on: 0808 808 0000

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 how you 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 a body part 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, and the ability to have a baby (fertility). See page 23 for more information on fertility

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 deal with how I feel about changes to my body?

The tips below can help you manage 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 your body.

- Talk to others who are going through or have been through a similar thing. It'll help to hear how they managed 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 managing 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 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 your cancer coming back (called 'relapse' or 'recurrence'). You may feel lost and alone or be worried about leaving behind the huge 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 people who have experience of primary bone cancer through blogs or on social media.

Our team at 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

After you finish treatment your doctors will monitor you for a long time. This is called 'follow-up care.'

You will need to make outpatient hospital visits on a regular basis. For example every 2 to 4 months for the first 3 years after finishing treatment, every 6 months for 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 for 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 healthcare team 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 work. You could even plan a trip for next year.

What if the Ewing sarcoma comes back?

Sadly, Ewing sarcoma 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 and 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 Ewing sarcoma

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.



Questions to ask your medical team

Being diagnosed with Ewing sarcoma 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. 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 about diagnosis

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

Questions about 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?
- How might the cancer and treatments affect my ability to have a baby (fertility)?
- 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 about follow-up care and support

- 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 support is available for me. For example at school or work?
- Is there financial help available after treatment?



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 Ewing sarcoma. Here is a list of some of these words, with explanations about what they mean.

A

Actinomycin D: A chemotherapy medicine used to treat primary bone cancer. It is called an 'anti-tumour antibiotic'. Actinomycin stops cells from dividing properly by damaging (breaking) DNA.

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.

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.

Diaphysis (Shaft): The main part of a bone and where Ewing sarcoma might start.

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.

Doxorubicin: A chemotherapy medicine used to treat primary bone cancer. 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.

Epiphysis: The growth areas near the ends of a bone.

Etoposide: A chemotherapy medicine used to treat primary bone cancer. Etoposide is a white powder, which is then made into a colourless liquid. It is usually given into a vein by infusion. It is a 'topoisomerase II poison' and stops DNA from fixing itself, this destroys the cancer cells.

Euro Ewing 2012: The standard chemotherapy given to treat Ewing sarcoma is now internationally recognised as the VDC/ IE arm from the Euro Ewing 2012 (EE2012 trial) both before and after surgery. The medicines given are called 'Vincristine', 'Doxorubicin', 'Cyclophosphamide', 'Ifosfamide' and 'Etoposide'. VDC/IE is now the new standard of chemotherapy treatment for Ewing sarcoma patients in the UK.

Ewing sarcoma: A rare cancer that can start in the bones or in soft tissue like the muscles. It is named after James Ewing, the doctor who first identified it. Ewing sarcoma is the second most common primary bone cancer in children and young people.

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 of '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

G-CSF (Granulocyte Colony Stimulating Factor): A growth factor that tells the bone marrow to make white blood cells. G-CSF is often given before harvesting stem cells. There are different types of G-CSF.

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.

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 used to treat primary bone cancer. Ifosfamide is an 'alkylating agent'. It works by damaging DNA so it cannot copy itself. This makes it difficult for the cells to divide.

Iliac: The area around the ilium, the largest bone of the pelvis.

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 (when you find it hard to poo or poo less often). 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.

M

Malignant: A 'lump' or 'growth' of tissue made up from cancer cells, that keeps 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 site (primary site), to other parts of the body. This means the cancer has spread.

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

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.

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.

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 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. Healthy tissue close to the tumour is less likely to be affected by PBT than standard 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 site (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 site (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 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.

Serum: A clear liquid that remains after blood cells and clotting proteins have been removed from a blood sample.

Side Effects: When medicines that people are given to treat a disease also have an effect on 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.

Stem Cell: A cell made from bone marrow that can divide and turn into a different type of cell, such as a blood cell.

Stem Cell Harvest: Where stem cells are collected from a person's blood. They are stored and then given back (transplanted) when needed. Stem cell harvesting is done so that blood cells destroyed by cancer treatments can be replaced in a stem cell transplant.

Stem Cell Transplant: Where blood cells that have been destroyed by cancer treatments are replaced by new blood cells. In people with primary bone cancer, stem cell transplants usually happen at the same time as high dose chemotherapy.

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.

Topotecan: A chemotherapy medicine used to treat some types of cancer. Topotecan works by stopping an enzyme called'Topoisomerase I'. This damages the cell's DNA, destroying the cell.

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. A typical cycle for primary bone cancer treatment could be 3 weeks.

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.).

Vincristine: A chemotherapy medicine used to treat Ewing sarcoma. It is given directly into a vein by infusion (drip). Vincristine stops the cancer cells dividing.

W

White Blood Cells: Cells that are part of the immune system. They help the body to fight 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 2026, 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. Users are involved in the development of health information.
6. Information is written to meet the needs of the audience.
7. Information complies with GDPR and other regulations
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.
- 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.
- Access to patient stories and the opportunity to get in touch with others, who have had similar experiences.
- Financial Assistance Grants for every new patient in the UK.
- Confidential and professional support from our dedicated team.
- 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 Ewing sarcoma, 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 Ewing sarcoma.

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

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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).**

Blood Cancer UK

Support for people living with blood cancer.

Website: bloodcancer.org.uk

Call: 0808 2080 888

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

CCLG (The Children & Young People's Cancer Association)

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 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 specifically for teenagers and young people 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: moveagainstcancer.org

Call: 0785 680 1687

Shine Cancer Support

A community of support for people in their 20s, 30s and 40s who are living with cancer.

Website: shinecancersupport.org

Call: 0780 447 9413

Teenage Cancer Trust

Care, support and information for young people with cancer.

Website: teenagecancertrust.org

Call: 0207 612 0370

Trekstock

Lots of information and support for people in their 20s, 30s and 40s who are living with cancer.

Website: trekstock.com

Call: 0204 541 7601

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

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- Dr Liz Roundhill, (Research Fellow, University of Leeds).
- Professor Bernadette Brennan (Consultant Paediatric Oncologist, Royal Manchester Children's Hospital).
- Professor Paul Cool, (Orthopaedic and Oncological Surgeon, Robert Jones & Agnes Hunt Hospital).

Reader Panel

- Vathsan Ravindran, Nicole Croft and Nicholas Massey and Isi Cooper.

Bone Cancer Research Trust Team

- Dr Zoe Davison, Dr Victoria Vinader, Joanne Wright, Dr Marianne Miles, Claire Utting and Marie Clegg.

Disclaimer

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Your feedback

We're always trying to improve our health information. If you would like to share any thoughts about this booklet, please get in touch. We'd love to hear from you.

Your feedback helps with the development of new resources and helps us to make sure our current resources meet your needs.

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

Comment on our social media:

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@bonecancerresearch

V5.0: SEP 26



Also available:
Leaflets and factsheets about Ewing sarcoma.

Please contact us to request your free copy or visit our website to view our printable/ downloadable resources.

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

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