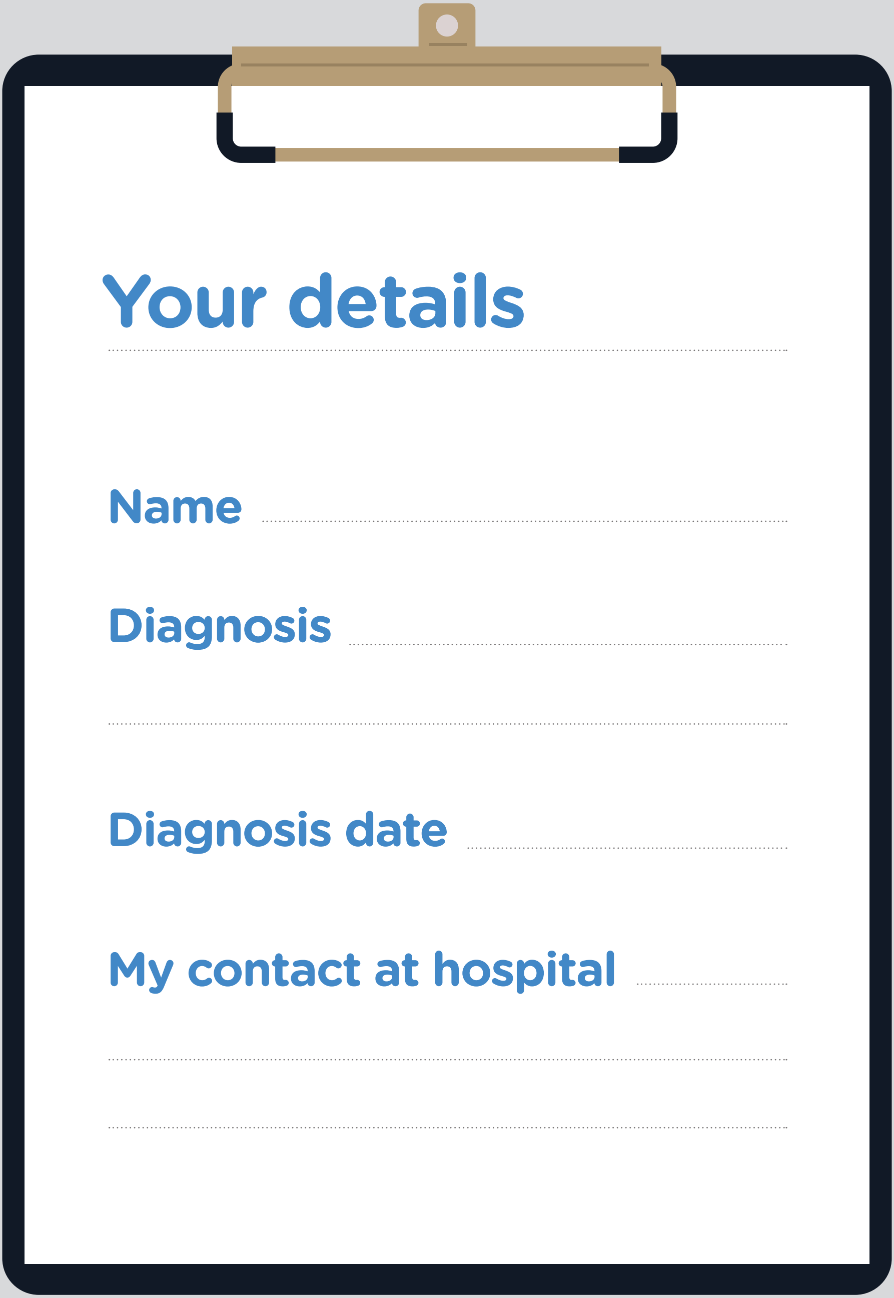
A STEP-BY-STEP GUIDE FOR PATIENTS

BONE CANCER RESEARCH TRUST



Your details

Name ....

Diagnosis ....

....

Diagnosis date ....

My contact at hospital ....

....

....

Welcome to your patient guide

Hello... and welcome to your patient guide!

There are likely to be lots of different things running through your mind right now – lots of emotions, unanswered questions and new information to take in. We have developed this Step-By-Step Guide to take the pressure off some of these aspects and create a place where you can store new information and write down your questions and thoughts.

You may wish to keep this guide with you throughout your diagnosis and treatment, or you may prefer to only use certain elements of the guide at certain times.

There is no right or wrong way to use this guide; we just hope it helps you in some way!

How was this guide developed?

At the Bone Cancer Research Trust we are constantly speaking to patients, family members and medical professionals to gain a better understanding of what information and support patients with primary bone cancer want and need. This allows us to work together to develop information that is required by patients at a time when things may feel like a bit of a blur or a whirlwind.

Throughout the guide, you'll find comments from others who have been affected by primary bone cancer and were happy to share their experience and personal advice. We hope you find these comments useful.

It is important for us to emphasise that this guide should not be used as a replacement to talking to your medical team, but rather used alongside your team to help direct you to certain areas they can help you with.

If you have any further questions after reading this guide, or wish to share your thoughts on the guide with us, please get in touch at

support@bcrt.org.uk

Best wishes, from the whole
Bone Cancer Research Trust team.

First things first

There is no right or wrong way to feel after receiving a cancer diagnosis. Everyone will feel differently and experience different emotions at this time.

It is completely normal to need to take some time out to come to terms with a diagnosis in order to prevent the feeling of being overwhelmed.

We feel that it's important for you to understand your diagnosis and what will happen next. This information can help you feel a better sense of control and get rid of some of the concerns or uncertainties playing on your mind. You may wish to know things in lots of detail, or in a more general way – whichever you prefer is perfectly OK.

Whatever information you wish to know, it is important not to be afraid to ask questions.

Doctors and nurses are used to explaining things, so if you have any questions or need help and advice with something, don't be afraid to ask...and ask again if you're still unsure!

For enquiries
please contact us on:
0800 111 4855
support@bcrt.org.uk

We recommend you use your Step-By-Step Guide alongside our other information resources. Please visit:

bcrt.org.uk/information

To order our printed resources for delivery to your home or hospital ward visit:

bcrt.org.uk/requestinformation

Contents

Interactive pages ......✎

Your journal ✎

Being diagnosed

Your medical team

Your treatment

Coping

Support

Useful bits

My medical team

You can use this space to write down who your medical team consists of and how best to get hold of them should you need to. In your Step-By-Step Guide you will find details on each member of your medical team in the 'Who's Who' section.

Clinical Nurse Specialist (CNS) or 'Key Worker'

Name	
Location	
Contact details	

Oncologist

Name	
Location	
Contact details	

Surgeon

Name	
Location	
Contact details	

Physiotherapist

Name	
Location	
Contact details	

Dietician

Name	
Location	
Contact details	

Social Worker

Name	
Location	
Contact details	

Add your own contacts in the space below

Appointments

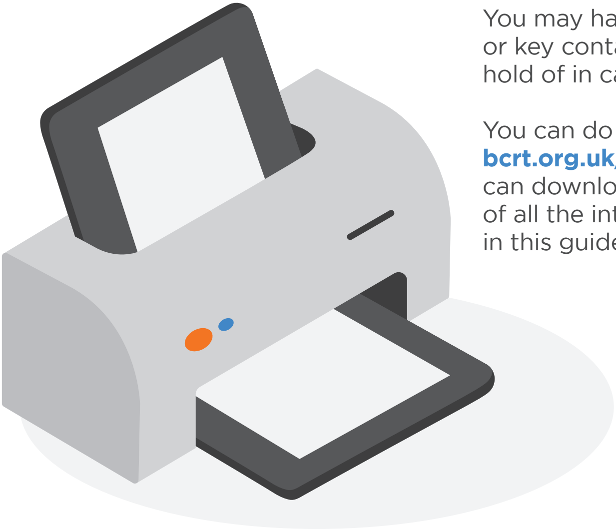
As your treatment begins you will need to visit the hospital more frequently for your appointments.

These appointments may be to undergo certain tests or to receive your treatment - such as chemotherapy or radiotherapy. It is likely that you may need to stay in hospital for longer periods of time at some point during your treatment, which will involve staying overnight on the ward.

This section of your guide allows you to note down and keep track of your appointments.

It may also help to pin the details of your hospital, and a key contact, to somewhere obvious at home should you need to contact them in between your appointments.

You can do this by filling in and tearing out the next page, called ‘My Hospital’.



You may have more than one hospital, or key contact, that you wish to keep hold of in case of emergencies.

You can do this by visiting: **bcrt.org.uk/patientguide** where you can download and print more copies of all the interactive pages you find in this guide.

My Hospital

Name	
Address	
Ward name	
Key contact	
Contact number	

On page 51 of your Step-By-Step Guide you will find a list of symptoms that may require you seeking medical advice. We suggest you keep this list and your 'My Hospital' details somewhere visible at home (the fridge is a popular spot!), in case you need this information when you are away from the hospital.

Keeping track

During your diagnosis and treatment you will require various visits to the hospital to undergo tests and scans and to receive your treatment.

These appointments may take place with different members of your medical team or even in different locations, depending on the kind of appointment you are having.

To help you keep track of this, the following pages provide you with space to write down your upcoming appointments, who they are with and where they are taking place.

Handy tips for appointments

- Note down any questions, concerns or symptoms you wish to discuss before the appointment so you remember everything you wanted to mention.
- Write it down! Better yet, bring along a family member or friend who can do this for you during the appointment while you speak with the doctor.
- Bring refreshments and some activities with you in case you have to wait longer than expected for your appointment.
- Take down the contact details of members of the team that you may wish to speak to at a later date.

> **Even when things are incredibly tough - keep going - sometimes it can feel like you’ve taken ten steps back, but then good news comes your way and keeps you going!”**
>
> **Parent of patient, aged 19 at diagnosis**

Name	Who with?	Where?	Notes

Name	Who with?	Where?	Notes

Name	Who with?	Where?	Notes

Getting to grips with treatment

Before your treatment begins, your medical team will work to design a treatment plan that will work best for you as an individual – they may even speak with doctors or surgeons in other hospitals to see what they think.

You will be told all about this treatment plan and given the opportunity to ask any questions and clear up any uncertainties. Your doctor will complete a 'Treatment Summary' that you are able to keep a copy of to share with your GP, or at any other appointments.

However, you may wish to keep track of the treatment you have received, or will be receiving in the future, in your own words. You can refer to this at any time, or use it to help you explain your treatment to family or friends.

You may find it useful to fill out the grid on the next page alongside your clinical nurse specialist.

Ewing sarcoma patients may be discussed during a NEMDT meeting. This stands for 'National Ewing Multidisciplinary Team' and allows a patient's treatment plan for surgery or radiotherapy to be discussed by experts across the UK. Get in touch with us if you want to know more, or ask your key worker for more information.

You can download and print further copies of Page 16, 'Your Treatment Plan' on our website to allow you to complete this plan for your different treatment cycles. visit:

bcrt.org.uk/patientguide

My treatment plan

What treatment will I receive?	Estimated timescale for my treatment	what are the possible side effects of my treatment?	what medication will relieve my side effects?
What treatment will I receive?	Estimated timescale for my treatment	what are the possible side effects of my treatment?	what medication will relieve my side effects?

> Laugh! Find something every day to laugh at, no matter how bad things are. The times you laugh help you get through the bits where laughter is impossible.”

Patient, aged 16 at diagnosis

What is primary bone cancer?

You're probably already aware of what cancer is. There is lots of information written about cancer and you've probably heard about it in the news or read about it online - but it is important to remember that not everything you read may be correct or reliable.

We provide lots of information on primary bone cancer and the specific types on our website, **bcrt.org.uk/information**. So it is probably best to start here when you want to learn more about your diagnosis or treatment.

Your medical team will also be able to point you in the direction of accurate and trustworthy information if you are ever unsure where to look.

If you have any questions about cancer in general, or how it develops, get in touch with us and ask!

A wide range of information may make you feel slightly overwhelmed while you try to come to terms with your diagnosis. With this in mind, it may help to start with the basics...

The basics

The body is made up of 37 trillion cells (that's 37,000,000,000,000) that grow and divide to keep the body healthy and able to function. If a cell gets damaged, it will quickly be replaced by a new cell.

However, sometimes these new cells are produced when they are not needed and this can create a mass of abnormal cells which grow and divide faster than normal cells do. This is what forms a lump called a **tumour**.

Tumours may be **benign**, meaning they are not cancerous, or they may be **malignant**, meaning they can grow faster and are cancerous.

Did you know?

Bone sarcoma is another term for bone cancer.

There are over 200 different types of malignant tumours (which are referred to as cancers) and this is because there are many different types of cells that form different areas and functions of the body.

What are the symptoms of primary bone cancer?

The symptoms of primary bone cancer can be general and appear similar to less severe musculoskeletal disorders, sporting injuries or even growing pains.

Patients may suffer from differing symptoms, or present with some symptoms more severely than others.

The most commonly reported symptoms of primary bone cancer are:

- **Bone pain** – this may gradually become worse over time and the pain can increase at night. It may be a continuous pain or pain that comes and goes (which is known as **intermittent** pain).
- The area may be **tender** or a lump or swelling may be felt.
- Patients may develop an **unexplained limp** or other issues with mobility (such as stiff joints or reduced movement).
- The bone may fracture.

Alongside these main signs and symptoms, patients may feel fatigued (tiredness), have a fever or night sweats, experience changes in their weight or muscle tone or suffer from bruising more easily.

Primary bone cancer is a cancer that develops from a cell within the bone

Every year around 562 people in the UK develop primary bone cancer.

Who can primary bone cancer affect?

Anybody can be affected by primary bone cancer (which is also referred to as a ‘**bone sarcoma**’).

Although this form of cancer is rare, it can affect a wide range of age groups.

Certain types of primary bone cancer, such as Ewing sarcoma and osteosarcoma, are most commonly found in teenagers and young adults. Other types, such as chondrosarcoma and chordoma, are more common in older adults.

However, all types of primary bone cancer can affect any age group; from young children to older adults.

What causes primary bone cancer?

We don’t know the cause of primary bone cancer, but we do know that it is not contagious and it does not develop because of something you did or a lifestyle choice you made.

There is nothing you could have done to avoid a primary bone cancer developing and due to its rarity, it is very unlikely that anybody else in your family will develop it.

> **It sucks, no two ways around that, but having some form of outlet can be really important. If there’s a particular hobby you do, TV series, book, games; do them all! Learn from others and help others who are going through it. Most importantly it’s okay to get upset, don’t bottle anything up. It’s hard to do but trying to accept it does make it easier to deal with. Failing that, never underestimate the power of a brew and chocolate biscuit!”**
>
> **Patient, aged 14 at diagnosis.**

The different types

There are different types of primary bone cancer….7 to be exact.

The 4 most common types of primary bone cancer are:

- **Chondrosarcoma**
- **Osteosarcoma**
- **Ewing sarcoma**
- **Chordoma**

The remaining 3 types of primary bone cancer are:

- **Spindle cell sarcoma of the bone**
- **Angiosarcoma of the bone**
- **Adamantinoma**

Many of these 7 types have ‘subtypes’ which may be treated in slightly different ways.

The different types (and subtypes) are classified by the way the tumour appears on imaging scans and when a sample of the tumour is analysed under a microscope following a diagnostic biopsy; this is known as pathology.

The pathology of primary bone cancer is quite complex, but knowing the type and subtype of cancer ensures you receive the best treatment.

> **BCRT are there to ‘hold the hand’ of people given a bone cancer diagnosis. They are accessible and always on the end of the phone, able to provide information or signpost to someone that can. They act as a necessary communications link between fellow sufferers, while fighting hard to raise awareness of primary bone cancer.”**
>
> **Primary bone cancer researcher**

Diagnosis

The first stage in diagnosing any type of primary bone cancer is usually a trip to your GP or A&E department in regard to symptoms you are concerned about. To learn more about symptoms, please see page 19.

Following an examination and an X-ray, patients with suspected primary bone cancer will be referred to a medical team specialised in diagnosing and treating this cancer type.

> **I went from being shy and quiet to someone thrust to the centre of attention and consequently became a lot more confident as I handled the increased attention and the interest of others.”**
>
> **Former patient, aged 22 at diagnosis.**

Tests and scans...

If a primary bone cancer is suspected you will undergo additional tests and scans.

These tests will confirm if you have cancer and determine its type, size, whether it has spread elsewhere in the body and your general health.

Essentially, these tests allow doctors to find out all they need to know about your cancer so they can treat it effectively.

During your diagnosis and treatment, going for tests and scans will become a regular thing. These tests will be used when you’re first being diagnosed and will also be used throughout your care to see how your body is responding to treatment.

We have provided some information on the most common tests and scans you are likely to receive. Most of these are quick and routine tests, though some may be slightly more uncomfortable.

Learning how these tests will be carried out and what to expect can ease any worries you may have. If you have any questions regarding the tests you will have, or want to find out more on any of these tests, please ask a member of your medical team to talk you through this.

Waiting for your test results can be a time of anxiety and uncertainty. Depending on the test carried out, results can take from a few days to around 2 weeks to be ready. It is best to chat with your nurse to ensure you know the time frames to expect.

It is likely that you will undergo some of the following tests and scans...

Blood Test

Blood tests are carried out during diagnosis to detect certain chemicals released by the tumour (known as tumour markers). They are also carried out before, during and after treatment to monitor how well the treatment is working and how your body is responding to treatment.

X-Ray

An X-ray is a picture (known as a radiograph) that is taken of the bones. This is likely to be the first imaging scan used to diagnose primary bone cancer and the results are used to detect swelling, abnormal bone growth or the breakdown of an area of bone.

Bone Scan (also called Nuclear Medicine Scans)

Bone scans look for abnormalities in the bones and often show these abnormalities clearer and earlier than an X-ray would.

Before having the scan, you will receive an injection containing a tiny amount of a harmless substance known as a radionuclide. This radionuclide is taken up by the bones over a few hours and can be detected by a camera. The radionuclide will collect in larger amounts in abnormal areas, allowing the location of the tumour to be determined.

CT Scan

A CT (Computerised tomography scan) takes a number of X-ray pictures from different angles to form a 3D image of the area of the body being examined. It should take around 5-10 minutes to complete and during this time you will be required to lie still on a bed as it moves through the scanner.

You may be given a harmless injection of a ‘contrast solution’ before your CT scan. This solution helps certain areas of your body show up more clearly on the CT scan and so makes it easier to interpret the results.

MRI Scan

An MRI (Magnetic Resonance Imaging) scan is similar to a CT scan, but uses magnetism and radio-waves instead of X-rays to build up a detailed 3D image of the tumour. You will be required to lie still on a bed as it moves through the scanner.

An MRI scan can take anywhere between 15 and 90 minutes to carry out. The scanner can make loud tapping noises at points during the scan, but you are able to wear headphones if this makes you feel more comfortable.

An MRI scan provides a picture of where the tumour is in the bone and can help doctors decide on the right treatment plan. Just like a CT scan, you may be required to receive a harmless injection before an MRI scan to help make the results clearer.

PET Scan

A PET (Positron Emission Tomography) scan examines the whole body and can therefore take around an hour to complete.

You will usually be asked not to eat anything for around 4 to 6 hours before the scan takes place and you will receive an injection of a harmless substance known as a radiotracer, which is taken up by cells that are active.

As cancer cells grow and divide much more rapidly than healthy cells, they take up the radiotracer much more and can be easily located during the PET scan; creating a 3D image showing the number of cancer cells in a certain area.

Biopsy

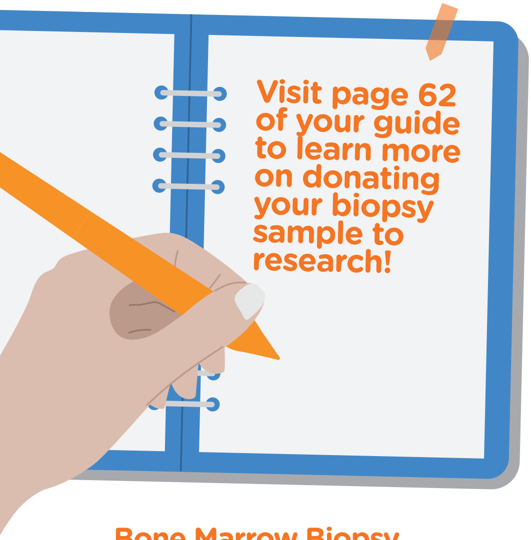
Other tests and scans can provide information on the size, location and extent of the tumour. However, in order to confirm the diagnosis and the specific type and severity of the tumour, a biopsy is required.

A biopsy is a specialist procedure that removes a small sample of the tumour so it can be examined under a microscope. Before this is carried out you will be given pain relief or an anaesthetic to ensure you feel comfortable during the procedure.

Children will have a biopsy taken while under general anaesthetic.

The small sample may be taken using a needle biopsy, to draw out small amount of the tumour tissue using a hollow needle, or by an open biopsy, which removes a small amount of tumour tissue during a minor operation.

Results from a biopsy can take up to two weeks to analyse but they enable doctors to confirm the presence, specific type and severity of your primary bone cancer diagnosis.



Visit page 62 of your guide to learn more on donating your biopsy sample to research!

Bone Marrow Biopsy

The **bone marrow** is the soft and spongy tissue inside some of your bones. The bone marrow produces **stem cells** which develop into our blood cells.

During treatment, a bone marrow biopsy is sometimes taken to help doctors monitor the development of blood cells and track how your body is responding to treatment. It can also determine if the cancer has spread into the bone marrow.

A needle is inserted into the hip bone (the pelvis) to withdraw some bone marrow, which will be assessed in the laboratory.

During a bone marrow biopsy, you will either be given a sedative to help you relax or a local anaesthetic to make the area go numb. Children will have a bone marrow biopsy taken while under general anaesthetic.

Audiogram

An audiogram is a hearing test. Some chemotherapy drugs can affect your hearing and so if you are being treated with these drugs, an audiogram will be taken before, during and after your treatment to check there are no changes in your hearing.

Electrocardiogram (ECG)

An electrocardiogram is a painless and non-invasive test that measures the electrical activity of the heart. Some chemotherapy drugs can affect the heart and so this test will likely be carried out before, during and after treatment as well as during follow-up checks after treatment to ensure there are no effects.

Cancer and fertility

Cancer treatments can affect your fertility (your ability to have children). The effect on your fertility will often not be known until much later after your treatment has finished.

It may seem like an odd thing to think about right now, but it is worth discussing with your specialist nurse before your treatment begins, as there are possibilities to preserve fertility in order to help you have children in the future.

For more information and advice visit: **macmillan.org.uk**

Grading and staging

It's likely that one of the big questions on your mind is in regard to how advanced your cancer is and if it has spread elsewhere in the body.

During diagnosis these questions will be answered and are referred to as the **'tumour grade'** and **'tumour stage'**.

It is important that the grade and stage of a cancer is determined, as this has a large impact on the treatment plan that you will receive.

Tumour grade

The grade refers to the behaviour of the tumour and is determined by assessing the tumour cells appearance under a microscope and comparing them to the appearance of normal, healthy, bone cells. Primary bone cancers are classed as low-grade or high-grade.

Low-Grade: these tumours are slow-growing and unlikely to spread elsewhere in the body. The tumour cells look similar to healthy cells when assessed under the microscope.

High-Grade: these tumours grow at a much quicker rate and are more likely to spread elsewhere in the body. The tumour cells look very abnormal when assessed under the microscope as these cancers are more advanced.

Tumour stage

The stage refers to how big the tumour is and if it has spread from its original location to neighbouring tissues or to distant organs in the body.

Primary bone cancers are usually staged using '**The Enneking System**'; which is a surgical staging system allowing **orthopaedic** surgeons to determine how much bone needs to be removed during surgery.

> **Focus on small wins and good days."**
>
> **A friend of 64 year old patient.**

The stages of primary bone cancer are 1A, 1B, 2A, 2B and 3:

Stage 1A: These cancers are ‘low-grade’ and are still confined to the bone they originated in. Therefore, the cancer has not spread to any other areas of the body or neighbouring tissues.

Stage 1B: These cancers are ‘low-grade’ but the tumour has grown through the bone wall in which it started.

Stage 2A: These cancers are ‘high-grade’ but are still confined to the bone in which they originated in. Therefore it has not spread to any other areas of the body.

Stage 2B: These cancers are ‘high-grade’ but the tumour has grown through the bone wall in which it started, and into neighbouring tissues.

Stage 3: These cancers are ‘high-grade’ and have spread from the bone they originated in to other bones, or other areas of the body.

When primary bone cancers reach stage 3, they most commonly spread to the lungs or other bones in the body.

This terminology can be quite difficult to understand, and differs between cancer types. Ask your medical team to explain how staging and grading works for your type of cancer and what this means for your treatment plan.

If the ‘Enneking System’ is not used, your tumour will be graded by a ‘TNM’ system. This stands for Tumour, Node, Metastasis and measures how big the tumour is (T), whether the tumour has spread to your **lymph nodes** (N) and whether the tumour has spread elsewhere in the body (M).

Getting answers

Being diagnosed with cancer can be a stressful and overwhelming time. It is often difficult to gain all the information you would like to while speaking with your surgeon, oncologist or any other member of your medical team.

It is certainly not uncommon to leave an appointment or discussion with some unanswered questions. You may even think of questions when at home or when your medical team are not around.

Here is a list of just a few of the questions you may wish to ask your medical team during your diagnosis. Think of these as a starting point and don't be afraid to ask any other questions you may have. If you don't understand something, ask your doctor or nurse to repeat themselves until you do!

> **Question everything, make sure you understand everything and investigate all the possible options."**
>
> **Parent of a patient, aged 13 at diagnosis.**

About your diagnosis

- Do you know the size and location of my cancer?
- How can I manage my symptoms?
- What shall I do if my symptoms become worse?
- Are there any activities I should avoid to help my symptoms?
- Will I need to make any changes to my day-to-day life, diet or exercise following my diagnosis?
- Who can I contact if I have any further questions, and will I be able to do so during out-of-office hours?
- Where can I find further information on my cancer type?
- What websites shall I go to for accurate information and advice?
- Who can I talk to if I am feeling overwhelmed with my diagnosis?

There's no such thing as a silly question.

You will be cared for by a team of experts who specialise in treating patients with primary bone cancer.

Meet the team

You will be cared for by a team of experts who specialise in treating patients with primary bone cancer.

However, these experts may not all be in the same hospital, or the hospital you visit may differ depending on what care you need.

Where will I be treated?

You will usually be diagnosed and usually have your surgery at a bone cancer centre. There are 5 centres in England.

Other treatments, like chemotherapy and radiotherapy, can take place at different hospitals around the UK.

Ask your clinical nurse specialist or ‘key worker’ more about this if you are unsure of where you will receive your care. It’s a good idea to get contact details from each hospital in case you ever need them.

Who will I be treated by?

Specialists in many different areas of medicine work together as a **multidisciplinary team** (known as an MDT) to care for patients.

The exact makeup of your MDT will depend on your age, the type of cancer you have and the care you personally require. All of the specialists in your team have very important roles to play, but you may see some of them more often than others.

Meeting all of your MDT can sometimes be overwhelming. In this section of your guide we have listed all the job titles you may come across during your time in hospital and have provided room for you to write down the name and contact details of members of your team that you may wish to get in touch with from home.

Who's who?

We've mentioned the importance of turning to your medical team with any questions, concerns or requirements you have - so it is important you know who your team are and how they can help you!

Orthopaedic Surgeon

A specialist in carrying out surgery on the bone. They will perform the surgery needed to remove the tumour during your treatment.

Oncologist

A specialist doctor who looks after people with cancer and is an expert in this area of medicine. You may meet different types of oncologists, such as; a 'Clinical Oncologist' who treats patients using radiotherapy and chemotherapy, a 'Medical Oncologist' who treats patients using chemotherapy or a 'Paediatric Oncologist' who treats children.

Clinical Nurse Specialist (CNS) or Advanced Nurse Practitioner

A nurse specialised in caring and supporting patients with cancer. Every person diagnosed with bone cancer should have a 'named nurse' or 'key worker' to have direct contact with and who they can talk to if they have any questions or concerns. This is a really important contact for you and your family to have.

Ward Nurse

A nurse who carries out day-to-day care and support roles while you stay on the ward; such as providing ongoing treatment, giving injections or taking blood samples.

Physiotherapist (Physio)

An expert in helping patients regain strength and movement to remain active after treatment by giving set exercises and activities for patients to carry out before, during and after treatment.

Occupational Therapist

An expert in helping patients regain their independence and ability to carry out everyday activities, both during and after treatment, by maintaining a patient's physical and psychological skills.

Dietician

An expert in ensuring a patient is receiving all the nutrients and dietary requirements they need during their treatment and recovery.

Community or District Nurse

A nurse providing care at your own home.

Paediatric Nurse

A nurse providing care for children.

General Practitioner (GP)

A GP is often the first point of contact during diagnosis and care for patients when they are back at home. Your GP will be in contact with your clinic doctors to keep informed about your treatment and the care you need.

Pathologist

An expert in studying the body's tissues using laboratory techniques. This allows them to identify cancer, its specific type and its severity.

Radiologist

An expert in assessing cancer by looking at the images produced by X-rays, MRI, CT, PET or bone scans. They look for signs of cancer during diagnosis and monitor a patient during treatment to see how well it is working.

Radiographer

Operate the machines that give patients radiotherapy treatment. They also operate X-ray, MRI, CT and PET scanners, which are all used during the diagnosis and monitoring of cancer.

Social Worker

A trained professional who can help a patient, and their family and friends, adjust to life during and after cancer treatment. You can talk to a social worker about emotional or practical issues, such as managing family life, your finances, work or school. If you are under 25 you and your family should have access to a Young Lives vs Cancer social worker.

Psychologist/Counsellor

A trained professional who will help patients and their family and friends talk about the emotional, social and educational issues that they may face during or after cancer treatment.

Pharmacist

An expert in the drugs used to treat cancer. They can tell patients more about these drugs, their doses and their potential side effects and can also give advice on how to deal with these side effects or prescribe drugs to help overcome these effects.

Youth Support Coordinator

They will not be found on all wards as they are funded by Teenage Cancer Trust. They provide emotional support for young people with cancer and ensure younger patients can socialise and relax while in hospital.

At the beginning of your guide you will find space to write down the name and contact details of your medical team.

Getting answers

When your treatment begins it is likely that you will have some uncertainties and unanswered questions. It is important for you to gain as much information as you need, and to be involved in the decisions made about your care. In this section of your guide we have put together a list of just a few of the questions you may wish to ask your clinical nurse specialists or 'key worker' before your treatment begins.

Think of these as a starting point and don't be afraid to ask any other questions you may have. If you don't understand something, ask your doctor or nurse to repeat themselves until you do!

About your treatment

- What treatment will I receive?
- How was this treatment plan decided?
- How long will my treatment last?
- Where will my treatment take place?
- What are the side effects to this treatment and will I need medication to control these side effects?
- Will this treatment affect my day to day life, such as my ability to attend work or school?
- Am I at risk of any effects later on in my life, and if so, is there anything I can do to prevent these before my treatment begins?
- Will I need rehabilitation treatment, and if so, how will it be arranged and where will it take place?
- Will I need follow-up tests to ensure the treatment has worked?
- What benefits are available for me in terms of prescriptions or other financial help?
- What support is available for me?

It is important to ask your doctor about the late effects of treatment as early as possible as some chemotherapy drugs can have a long term impact.

Female patients may want to discuss freezing eggs or ovarian tissue and male patients may want to discuss sperm banking.

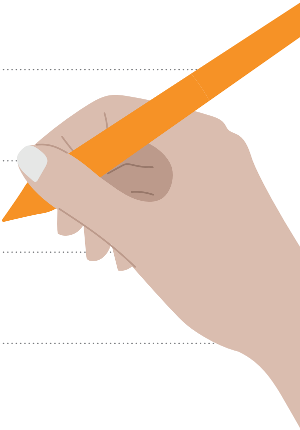
There's no such thing as a silly question!

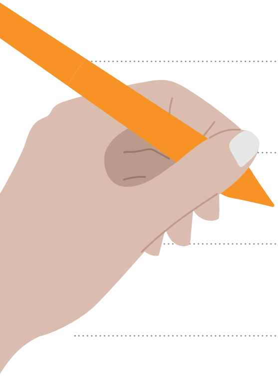
Your treatment plan is all about you and you have the right to be involved in decisions made about your care. Don't be afraid to make yourself heard.

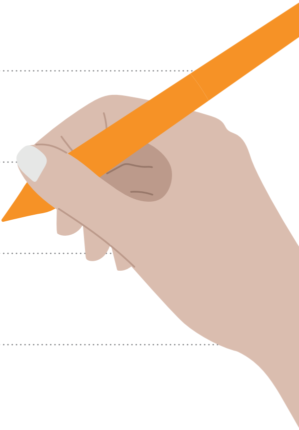
Notes

It can be hard to take in everything you hear, so you may find it beneficial to write down the information or answers you receive.

You can use this space to write down any questions, answers or general thoughts you have that you may wish to refer to at a later time.

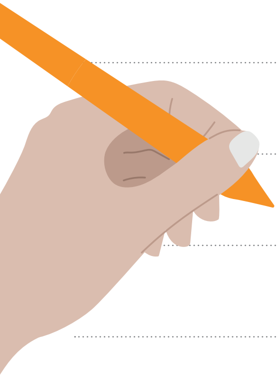






**Spend as much time as a family as possible!
Go on a day trip, make those happy memories that are outside of the hospital.”**

Sibling of 13 year old patient



Your medical team will design a treatment plan that suits you best as an individual.

Treatment

After receiving a diagnosis, your treatment plan can begin. Cancer treatment is different for everybody - even if you have the same type of cancer or the same doctor as somebody else.

Your medical team will design a treatment plan that suits you best as an individual, so it is difficult to say exactly what treatment you will receive and how you will receive it.

Your treatment plan will depend on:

- Your type of cancer
- The stage and grade of your cancer (its size and severity)
- Your general health

What we can tell you is that primary bone cancer tends to be treated by surgery, chemotherapy, and in some cases, radiotherapy. You may receive just one of these treatments or you may receive a combination of these different methods.

This is something your medical team can talk you through in detail, letting you know how long these treatments will last and the rehabilitation and support that is available for you during and after treatment.

Before treatment

Before your treatment begins, it is likely that you will undergo further scans and tests to confirm exactly what treatment is best for you as an individual.

Your medical team will discuss with you exactly what will happen during your treatment as well as the treatments benefits, risks, potential **side effects** and your recovery and rehabilitation plan.

As with all occasions, if you are unsure of anything you're told about your treatment or recovery, ask your doctor or nurse to repeat themselves or try explaining it in a different way.

You may hear lots of unfamiliar language flying about around you – check out our 'Jargon Buster' on page 91 of this guide for a breakdown on what some of these words mean.

Surgery

Most patients with primary bone cancer will undergo surgery to remove their tumour.

Surgery to remove a primary bone cancer is usually carried out by an orthopaedic surgeon. Although depending on the location of your tumour the surgeon's specialism may differ.

The surgeon will plan the surgery to ensure as many cancer cells are removed as possible, while creating as little impact to the bone's function and appearance.

Often a small amount of healthy tissue in the surrounding area is also removed to ensure the tumour can no longer grow or spread.

If the tumour is in your arm or leg, this procedure is known as '**limb-sparing**' surgery and may involve the affected bone being replaced by a bone that has been donated by somebody else or, most commonly, by a metal implant known as an **endoprosthesis**.

If your treatment involves surgery, you will be placed under general **anaesthetic** so that you won't feel, hear or see anything during the procedure. A specialist doctor called an anaesthetist will come and see you before your surgery to discuss this in detail and explain how this will take place.

If you have limb-sparing surgery on your leg as a child, you may later undergo a procedure known as leg lengthening. This is especially important if you are still growing. The procedure only takes a few minutes and is painless, but will require a visit to the hospital.

Did you know?

Limb-sparing surgery may also be referred to as limb-salvage surgery

Before treatment

In many cases, surgery is used alongside chemotherapy to ensure all the cancer cells are destroyed.

You may have surgery first or may receive chemotherapy before surgery in order to shrink the tumour and make it easier to remove.

Every patient has their treatment plan designed specifically for them and so the treatment and the scheduling of these treatments will differ from patient to patient.

If you're ever unsure of your treatment plan or the next steps, ask a member of your medical team to talk you through this.

The side effects of surgery

The side effects of surgery may differ depending on the extent of the surgery you have had. Before having surgery your surgeon will sit down with you to discuss all possible side effects and allow you time to ask questions.

The main side effects are the permanent changes this procedure may leave to your body; having a scar where the surgery took place is common. It is important to remember that scars will often fade over time and there is lots of support available to you from your care team and other organisations; which you can find on page 88.

Whether you want to learn more about skin camouflage products, feel low in confidence or would like support following surgery, there is always someone to talk to.

After surgery

After surgery you will need to stay in hospital for a short while. The hospital recovery time will depend on the extent of your surgery and the **rehabilitation** (referred to as rehab) required. During this hospital stay your pain will be monitored and painkillers will be offered as needed.

Rehab can start as soon as 24 hours after surgery and you will begin any physiotherapy you require. The exercises you will be given are really important to help strengthen your muscles while reducing the risk of an infection or a blood clot developing during your recovery.

You may have already been given some exercises to do before surgery.

This is known as prehab.

At this time, it is likely you will receive antibiotics. This is to ensure your wound is not at risk of infection as it heals.

There is more information on what happens after your treatment on page 64

If you are uncomfortable or in pain after your surgery, let your nurses know so they can help with this. Learn more on managing your pain on page 75.

Amputation

For around 15% of patients, limb-sparing surgery is not possible and either part of, or all of, the limb will need to be removed in a procedure called an **amputation**. The limb is often replaced by an artificial limb, which is called a **prosthesis**.

An amputation is required if the tumour has grown into the main blood vessels or nerves of the limb, making it impossible to remove the tumour without affecting these important structures.

If your medical team decide an amputation is the best treatment for you, they will explain this to you and give you the opportunity to ask any questions you have.

You may have lots of questions or feel lots of emotions at this time.

You may find it useful to talk to a **counsellor** or other patients who have had a similar procedure.

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

Recovery from amputation

After the operation you will find that a drain has been put into the remaining part of the amputated limb; which is referred to as the 'stump'. This drain is to take away any fluid that may build up after surgery.

It is common for patients to still feel the limb after an amputation, this is normal but if these sensations are causing you pain you should tell your medical team so they can help.

Limb-fitting centres

If you and your medical team decide an amputation is the best form of treatment for you, you will likely be referred to a 'Limb-Fitting Centre'.

At this centre you will be under the care of a range of specialists, including specialist nurses, physiotherapists and prosthetists (specialists in caring for people with artificial limbs).

The Limb-Fitting Centre will help you decide on the best prosthesis for you. You will work with them to learn to use your artificial limb and care for the prosthesis and your stump correctly.

The specialists at the Limb-Fitting Centre are also very experienced in coping with the emotional effects that come with an amputation. They can act as a fantastic support network for you and your family.

> **“Believe it or not, I went to college after my leg amputation and did a massage therapy course. Everyone there was so helpful and I really enjoyed it and didn’t feel out of place or that I couldn’t cope. It was an amazing experience.”**
>
> **Former patient aged 48 at diagnosis**

It is important to be honest with your medical team about your lifestyle and any other medication or recreational drugs you are taking (such as marijuana or non-prescription steroids). Other medication may affect your blood test results or the chemotherapy itself.

An example of this is the contraceptive pill, which can become ineffective during chemotherapy treatment and so other forms of contraceptive should be discussed with your medical team or GP if you are receiving chemotherapy.

Second opinions

There are national guidelines set out for the treatment of primary bone cancer, and your treatment plan will be discussed by multiple experts forming your multidisciplinary team (MDT) to determine the best care for you as an individual.

However, you are able to ask for a second opinion at any stage of your diagnosis or treatment. A second opinion is getting an opinion of a doctor or specialist who has not been involved in your care before. You may wish to gain a second opinion to confirm your diagnosis, for reassurance of your treatment plan or to make sure you are getting the best care possible. However, getting a second opinion may cause a delay to your treatment or you may need to travel to receive this.

Your specialist nurse, oncologist or GP can speak to you about this in further detail and give you advice on how to gain a second opinion. It is important to remember that requesting information on this will not offend your medical team or alter the care you are currently receiving.

Chemotherapy

Chemotherapy, often referred to as 'chemo', is the name given to the treatment of cancer using drugs that stop (or slow down) the growth and division of cancer cells or cause these cancer cells to die.

When will I have chemotherapy?

Chemotherapy may be the only form of treatment you receive, or it may be used in combination with other treatments.

It is often used before surgery to make the tumour smaller and easier to remove, or it may be used after surgery to destroy any remaining cancer cells in the body and lower the chance of the cancer returning.

Chemotherapy is given to patients in 'cycles', which involve treatment and rest periods. Patients tend to have chemotherapy over 3-4 days before having a rest period of around 2-3 weeks to allow the body to recover. This is classed as one 'cycle', and will be repeated over a set amount of time.

Your doctor will be able to tell you more about exactly how your cycles will be scheduled, how long they will last, what chemotherapy drugs you will receive and any possible side effects.

How will I receive chemotherapy?

You may receive one type of chemotherapy drug, or you may receive different drug types at once; which is known as combination chemotherapy.

The chemotherapy drugs patients receive and how they are administered differ from patient to patient.

You may receive chemotherapy daily, weekly or monthly and the length of time you receive this treatment for can also vary quite a bit depending on your tumour type and your response to treatment. This is something best discussed with your oncologist.

For more information on side effects, and our top tips on dealing with them, head to page 69.

As chemotherapy is absorbed into the blood, it is carried around the body reaching all the cancer cells. You may receive chemotherapy in a number of ways:

- As a tablet or liquid medicine that you swallow
- As an injection
- By an IV (intravenous) infusion

What is an IV infusion (intravenous Chemotherapy)?

Intravenous (IV) simply means ‘in a vein’ and is the insertion of a small tube (which is referred to as a ‘line’) into your vein.

During cancer treatment, it is likely that you will need various chemotherapy drugs delivered to your bloodstream. You may also need antibiotics, fluids and blood tests to monitor how you are doing.

All of these different things would mean a lot of injections, but an IV line can be inserted to prevent the use of multiple needles.

The IV line is connected to an IV pump, which ensures the liquid flowing into your veins by the IV line does so in the right amount and at the right rate. These IV pumps are often attached to a pole, or ‘drip stand’, that is on wheels; this is so that you can move around the ward during your treatment.

It is important to bear in mind that not all patients will require an IV line. Instead you may receive your treatment via injection or undergo blood tests that are taken by a needle inserted into your arm.

If you are unsure of needles or feel any pain when this is carried out, make sure to ask your nurse to numb the area beforehand using an **analgesic** cream, or try to switch arms when possible.

There are different types of IV lines:

A Cannula

A temporary IV line that will be inserted into your hand or arm. It is likely these will be put in for a specific treatment and so will be removed after a couple of days.

A PICC line (Peripherally Inserted Central Catheter)

A thin, flexible, tube that is inserted into your upper arm. From here, it feeds into the large vein just above your heart. You will receive an anaesthetic to have the PICC line fitted, so you won’t feel any pain.

PICC lines are more long term than a cannula, but are often used for short term treatments until a more permanent IV line can be fitted.

A Central Line (also known as a Hickman Line):

A thin, flexible, tube that is inserted into a vein in your chest; usually just below the collarbone. This type of IV line is inserted during surgery while you are under anaesthetic, so you won’t feel any pain. A Central Line can stay in for weeks, or even months if necessary, and the point where the line is inserted will need to be covered with a sterile dressing at all times; so you’ll need to be careful not to get this area wet.

A Portacath

Is very similar to a Central or Hickman Line and is often referred to as an ‘Implantable Central Line’ as the end of the Portacath line is completely under the skin. The Portacath is inserted during surgery and the thin, flexible, tube is inserted into a vein near the heart and connected to a small box which lies under the skin. Drugs, fluids or antibiotics can be administered by this small box using what is known as a ‘Huber needle’. When your Portacath is first inserted, the nurse may numb the area around where the small box is implanted while the Huber needle is attached; this is so you don’t feel any pain. After a short while, your skin will become used to this and, unlike a Central Line, there is no need for sterile dressings so you can shower and swim while having a Portacath fitted.

If you have any of the following symptoms, it may be because you have an infection. It is important to seek medical help in this case.

BONE CANCER
RESEARCH TRUST

- A high temperature (above 37.5°C)
- Your skin feels hot to touch
- You go from feeling hot to very cold and shivery
- Your muscles ache
- You feel confused or dizzy
- You are coughing or feeling short of breath
- There is pain, redness, swelling or discharge from a cut near your IV line.

Ask your nurse how it is best to get in touch should you feel any of these symptoms so you are well prepared.

You should also seek advice on how to prevent getting an infection.

Please be aware that each centre may have different guidelines about when you should contact your clinical nurse specialist or key worker. Ensure you have this information before heading home.

Tear out and keep

It made me reassess what’s important to me, my friends and family.”

A friend of a patient.

Radiotherapy

Radiotherapy is a ‘local therapy’, meaning it is designed to treat the tumour directly rather than reach the whole body like chemotherapy does.

Machines are used to target the tumour with a high-energy, focused, radiation X-ray beam which damages the DNA inside of the cancerous cells and causes them to die. This procedure is painless.

If you are having radiotherapy you will have detailed imaging scans beforehand in order to determine the most precise and accurate way to administer the radiation.

When will I have Radiotherapy?

Radiotherapy is used less frequently in the treatment of primary bone cancers in comparison to surgery or chemotherapy. However, it is used after surgery for the treatment of certain tumour types; such as Ewing sarcoma or chordoma.

Radiotherapy can be used to shrink the tumour before surgery takes place, remove any remaining tumour cells in the area after surgery, or it may be used in patients who cannot undergo surgery due to the location of their tumour (for example a tumour in the pelvis or spine).

Additionally, radiotherapy can be used to relieve the symptoms of primary bone cancer in patients with more advanced tumours.

What is involved when having radiotherapy?

Radiotherapy is given in ‘fractions’, which means the treatment dose is split over a number of different appointments.

A lot of patients have these over the course of a week and so will have 5 treatments, one a day from Monday to Friday, and the weekend as a rest period.

However, each patient will have their radiotherapy scheduled for them individually; so you may receive radiotherapy more often or less frequently than this suggested time scale.

Proton Beam Therapy?

Proton Beam Therapy (PBT) is a type of radiotherapy that delivers the radiation dose to the tumour and can stop delivering the dose just beyond the tumour; which reduces the dose to surrounding healthy tissues.

PBT is sometimes recommended as it may hold an advantage for bone tumours that are not very sensitive to conventional radiotherapy. It can allow a higher dose of radiotherapy to be used and may reduce the side effects patients face.

While there are possible benefits, each case has to be carefully examined. People are able to receive PBT at The Christie Hospital, Manchester and at University College London Hospital, London. Only a minority of patients are likely to benefit from PBT and your doctor will let you know if your case should be reviewed by an expert panel.

If you would like to find out more, speak with your doctor or get in touch with us at support@bcrt.org.uk or on 0800 111 4855 for more information.

Intensity-Modulated Radiotherapy (IMRT)

In recent years, advances in radiotherapy have led to the introduction of Intensity-Modulated Radiotherapy (IMRT).

IMRT allows a more targeted delivery of radiation, creating accurate and consistent treatments while allowing a larger radiotherapy dose to be administered.

IMRT is very similar to conventional radiotherapy as it uses high-energy, focused, X-ray beams to target the tumour and destroy cancerous cells. However, this method is more advanced and the X-ray beams can be shaped to target the tumour more accurately and from numerous directions to limit the radiotherapy effects to healthy tissue surrounding the tumour.

Other forms of treatment

Aside from the main three forms of treatment primary bone cancer patients receive (surgery, chemotherapy and radiotherapy), there are other treatment forms you may come across.

Immunotherapy and targeted treatments

You may have heard of cancer treatments such as immunotherapy, biological therapies or targeted treatments.

These treatments work by blocking the role of a specific **gene** or protein which is involved in the cancer cells growth and spread.

Immunotherapy does so by boosting the body's own immune cells to recognise and fight the cancer cells. In order to develop these treatments, scientist must first learn more on how each cancer type develops and what genes and proteins are involved in its progression.

At the Bone Cancer Research Trust we are funding research into how primary bone cancer develops and what specific genes or proteins may be targeted in order to develop new therapies.

You can learn more on the research we are funding at **bcrt.org.uk/research**

Mepact (Mifamurtide) is a therapy developed for osteosarcoma patients aged 2 to 30, whose cancer has not spread elsewhere in the body. Mepact is given after surgery and chemotherapy and works by stimulating the immune system into attacking the osteosarcoma cells.

Blood Transfusion

Cancer and cancer treatments can reduce the number of red blood cells in your blood. This is called **anaemia**.

As red blood cells carry oxygen around your body, anaemia can make you feel tired and out of breath.

It is not uncommon for a blood transfusion to be carried out to relieve these symptoms.

During a blood transfusion you will be given donor blood through a drip into one of your veins. This can be done as an outpatient or you may need to stay in hospital overnight.

A blood transfusion will increase your energy levels and patients usually see a difference within 24 hours of having a transfusion.

Before a blood transfusion you will receive lots of information to read and have plenty of opportunity to ask any questions you may have.

Stem-cell transplant

If you receive high-dose chemotherapy, you may require a stem-cell transplant.

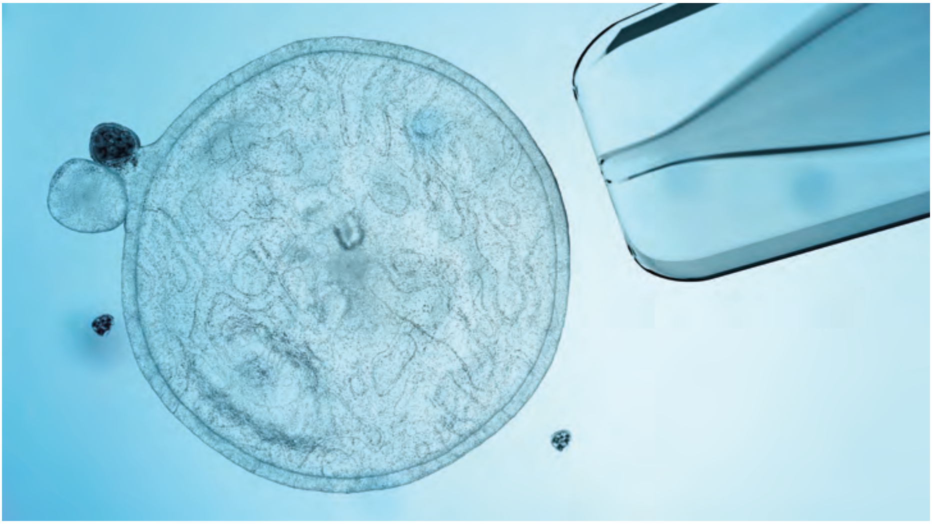
This allows the chemotherapy to have as high impact on the cancer as possible, while replacing important blood cells which may be damaged during this treatment; such as red blood cells, which transport oxygen around the body, and white blood cells, which protect the body from infection.

This treatment is most commonly used for Ewing sarcoma patients. Stem-cells, which are found in the bone marrow, are 'master cells' that can differentiate into any blood cell type. These stem cells are collected before high-dose chemotherapy begins in a process known as 'stem-cell harvesting'.

Before the cells are taken, you will be given an injection of a hormone, called G-CSF, which instructs the stem-cells to leave the bone and enter the bloodstream where they can be 'harvested' using a specialised machine.

Once removed, the stem-cells are stored and frozen until the high-dose chemotherapy is complete and the stem-cells can be transplanted back to you using an IV drip.

It can take a few weeks for the bone marrow to fully recover and new blood cells to be produced following a stem-cell transplant. During this time you will be at a higher risk of infection due to a low number of white blood cells and so antibiotics may be required to help prevent infection.



Clinical trials

Clinical trials are an area of medical research that aims to develop and improve treatments, to create safer and more effective techniques than the standard of care that is currently available.

You may be given the opportunity to enrol on a clinical trial. This section of your guide describes what clinical trials are.

What is a clinical trial?

Clinical trials are clinical studies that are crucial for the development of new treatments, diagnostic tests or surgical methods, and are the point at which these are first tested in people.

There are different stages of clinical trial, ranging from very early stage, which are usually called phase I or phase II to larger later stage trials, usually called phase III trials.

The aim of phase I and II trials is usually to find out the right dose to administer to patients and to understand any side effects the new treatment may give. These usually only take place in 1 or 2 hospitals and only recruit a small number of patients.

Once a safe dose is worked out and if the new treatment shows no serious side effects, these progress to a phase III trial.

Phase III trials are larger trials, usually needing to recruit hundreds of patients. The main aim of these trials is to understand if the new treatment is effective. As primary bone cancer is rare, phase III trials are usually international collaborations, and are open to patients in many hospitals.

A large multi-disciplinary team (MDT) of medical professionals will be involved in the trial, including researchers, doctors, nurses and social workers.

Ask your medical team about clinical trials

Unfortunately, there may not always be a clinical trial available for your cancer type or those available may not be suitable for you.

How do I join a clinical trial?

A clinical trial may be suggested to you by your medical team, or you may find out about a clinical trial online yourself.

Either way, you should always discuss the prospect of taking part in a trial with your doctor first to ensure the trial is suitable for you and to gain a medical referral.

Before looking into a clinical trial further, you must first determine if this trial is suitable for you and if you are able to take part. This information is known as '**eligibility criteria**'. Every trial has these criteria to ensure the participants of the trial are as similar as possible in order for scientists to compare the results accurately. Criteria may include your age, tumour type, tumour stage, previous treatment you have received and your general health, amongst many other things.

If you are not able or eligible to take part in a clinical trial, your medical team will explain this to you clearly and ensure you are following the most appropriate treatment

Taking part in a clinical trial

In order to take part in a clinical trial you must give 'informed consent'. Before consenting to a clinical trial, you will be given information to read about the trial and time to think about whether you wish to take part.

You must ensure you have been told everything you would like to know and understood all of the information before signing your consent.

You are able to withdraw from a clinical trial at any point if you wish to do so, and in most cases this will have no effect on the care and further treatment you receive.

The pros and cons

The treatment you receive during a clinical trial may or may not be better than existing treatments; that is what the trial is trying to find out.

However, during clinical trials patients 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 patients on a clinical trial will require more check-ups and tests than usual, and need to visit the hospital more often.

This can be difficult for some patients but knowing that by taking part in a clinical trial they may be helping other patients in the future can be a great bonus and a positive reason for lots of people.

Make sure you ask lots of questions and don't feel rushed to decide if it is right for you... it is a big decision to make!

The Bone Cancer Research Trust is proud to be a member of the Association of Medical Research Charities (AMRC), the national membership organisation of leading medical and health research charities.

amrc
ASSOCIATION OF MEDICAL RESEARCH CHARITIES

Other ways you can help research

Donating samples to research

The analysis of patient samples is crucial to carrying out high-quality research. These patient samples include blood, a sample of a tumour (which is taken during a biopsy or during surgery) or a sample of your healthy tissue.

Patients must always provide consent for these samples to be used for research and the doctor or nurse collecting the sample will firstly need your permission and signature of consent. The samples and data will be anonymised so that researchers cannot identify who has donated these.

All samples collected are put into a '**biobank**'; creating a library of patient samples and their relevant data, which are all anonymous and identified by a unique barcode. These samples can then go on to be used in both current and future research projects.

Other ways to be involved

Patient and Public Involvement (PPI) refers to patients, carers or other members of the public becoming involved in research.

Being involved may require you to input on the design of research projects, ensure research is shared in an understandable format or help develop information sheets for patients taking part in research.

The Bone Cancer Research Trust provide surgical centres treating primary bone cancer patients in the UK with grants to support the collection of patient samples and ensure these samples are used in high quality research studies.

Patient tissue samples can be destroyed at any time if you change your mind. However, if the sample has already been used in a research study then the results of this study will stand.

PPIP, the Patient and Public Involvement Panel of The Bone Cancer Research Trust ensures patient and public needs are at the heart of BCRT's research. To learn more visit: **bcrt.org.uk/research/public-and-patient-involvement-panel**

Speak to your specialist nurse about how you can donate your samples for research.

> **My husband has dealt with this incredibly well. He has bounced back and got on with life. But his outlook is changed and living life happily and in a fulfilling manner has become much more important."**
>
> **Partner of male patient, aged 49 at diagnosis.**

After treatment

The end of treatment will be a welcome relief, but it can also be a time of anxiety and worry. Many patients and families can feel a bit lost or lonely as the support of their medical team and hospital environment is left behind.

This is a perfectly normal feeling and a time when you may feel ready to reach out for support. See page 82 to find out more on what support is available and how to access it.

Before you leave the hospital, be sure to ask your doctor or key worker for any symptoms or signs to be aware of and how to contact them should you need anything.

Your main care will now be with your GP. They will have been updated on your care received in hospital and will also receive information on all your future **follow-up** appointments.

Follow-up

You will return to the hospital outpatient clinic for regular follow-up appointments after your treatment is finished.

Follow-up care is a way for doctors to keep an eye on you and ensure you are not suffering from any **late effects** of your treatment or a **recurrence** of the cancer. These appointments are also a good opportunity to bring up any emotional or practical issues you are facing.

Most patients will visit the hospital every 2 months in the first year after treatment, every 3 months in the second year, 4 months in the third and 6 months until the fifth year. After 5 years cancer free, follow-up appointments will be yearly.

It is best to check with your medical team how they think your follow-up appointment schedule will look.

Even after your treatment finishes, your clinical nurse specialist (also known as a key worker) is still around for you to call or email at any time!

Your follow-up appointments are a useful time to express any concerns you have, but it is important that you visit your GP if you experience any unexplained symptoms in between your appointments.

Rehabilitation (rehab)

Rehabilitation (also known as rehab) can start as little as 24 hours after surgery; but the exact timescale and the rehabilitation you will receive will largely depend on the treatment you have had.

Rehab is a form of therapy that enables patients to regain strength, learn to manage day-to-day activities and return to normal life as quickly and as smoothly as possible.

Primary bone cancer patients may see various medical professionals while in rehab, such as; social workers, physiotherapists, occupational therapists, dieticians, prosthetists (specialists in creating prosthetic limbs following an amputation) or orthotists (specialists in providing aids, such as special footwear, following surgery).

Rehab can be challenging and frustrating at first, but it is a very important part of your recovery so it's important to keep focused and motivated.

> **“Once I had finished treatment, there was a honeymoon period where I was glad to not have any hospital stays on the horizon. This however, wore off and I soon began to miss the support that came with my cancer. I felt a bit forgotten and lost. This was when I really began to need emotional support, as I was expected to just go back to my ‘normal’ pre-cancer self at school and home.”**
>
> **Former patient, aged 8 at diagnosis.**

Visit page 71 to learn more on 'long-term side effects' or 'late-effects' of treatment. It is best to get as much information about these effects as possible.

Rehab will help you and your family find ways to adapt to life with the changes caused by your treatment and surgery, enabling you to return to work or your studies as soon as possible.

Physiotherapists and occupational therapists will likely be your main point of contact during rehab and are there to answer any questions you may have.

Make sure you know how to reach your key contact when you're at home in case you have any questions about your rehab – your medical team are always more than happy to help!

What if my cancer returns?

Recurrence (also known as relapse) is when the cancer returns at a later date after treatment is complete. It may return to the same place the cancer was originally, or it may develop in a different area of the body.

It is natural to worry about the possibility of your cancer returning, but both your worries and the risk of the cancer returning will reduce over time.

Unfortunately, primary bone cancer can return, and some patients may relapse. There are treatment options available. You may receive more chemotherapy, radiotherapy and surgery. Though the exact treatment will depend on the treatments you originally received, and so it is difficult to say how this treatment path will look for individual patients.

As always, your medical team will talk you through your treatment plans and you will have plenty of opportunities to ask questions.

If treatment doesn't work

You may be told that there are no more treatment options available to cure your cancer. This is a very difficult time, but there is lots of support available to you.

Palliative care nurses support people whose cancer can no longer be cured and specialise in relieving symptoms to improve your quality of life.

Macmillan Cancer Care and Young Lives vs Cancer provide excellent information on coping with advanced cancer and end of life care.

Ask your nurse for these booklets or find these details in our 'Handy Contacts' list on page 88.

> **Focus on small wins and good days.”**
>
> **Friend of 64 year old male patient.**

Side effects

It is important to remember that everyone experiences different side effects and some may experience them more severely than others - so it is difficult to say exactly how you will feel during treatment.

Why does chemotherapy cause side effects?

In order to be effective, chemotherapy must take advantage of the difference between cancerous cells and normal, healthy, cells.

Cancer cells divide much more rapidly than normal cells and therefore chemotherapy works by targeting this rapid cell division process.

Most healthy cells divide slowly, but some cell types are fast-dividing (like hair-cells or cells of the digestive system), and these cells can be affected by chemotherapy. This is why patients can experience some unpleasant side effects.

Side effects can affect you in the short-term or longer term; which may be called ‘long-term side effects’ or ‘late effects’.

Short-term side effects

Short-term side effects may be unpleasant, but they will go away when your treatment is finished.

Examples of short-term side effects for chemotherapy are:

- Fatigue
- Nausea or vomiting
- Diarrhoea or constipation
- Hair loss
- Thrombocytopenia (a low platelet count)
- Changes in appetite
- Changes in weight
- Sore mouth or gums
- An unusual taste in the mouth
- Skin problems such as sensitivity or irritation
- A higher risk of getting an infection
- Trouble sleeping
- Memory and concentration problems

Radiotherapy and side effects

Radiotherapy also causes side effects, such as a reaction on your skin, but these depend largely on the area of the body in which you received radiotherapy

Examples of short-term side effects for radiotherapy are:

- Fatigue
- Sore skin
- Pain and swelling in the area you received radiotherapy

Let us know your best tips for dealing with side effects!

Dealing with short-term side effects and staying well

Your medical team can provide medication both before and during treatment to relieve some of these side effects. Each patient is different and so may not experience the same side effects or may not get them as severely as others may.

For this section of your guide we have provided some tips we think may help when dealing with these side effects.

Please do get in touch with us if you know of any other great pointers that we can share with others!

Hair Loss

This is the side effect most people are aware of and if you are affected (which you may not be!) it can begin any time from a few days or a few weeks into your treatment.

This happens because chemotherapy targets fast-dividing cells, which both cancer cells and hair cells are.

Everyone copes differently with this side effect, but the best thing to do is to try stay positive and remember that your hair will grow back once your treatment has finished.

During treatment, you may feel you want to wear a wig, head scarf, beanie or you may even wish to bare all by shaving your head before the hair loss starts – you could even raise money for charity while doing so!

Talking to your clinical nurse specialist or key worker about these options and tips on coping with hair loss may help. There are organisations that provide wigs to patients during treatment, or help with the costs, so you may wish to ask about this too.

Nausea and Vomiting

Doctors can provide anti-sickness tablets to help with this. It may be best to avoid food that is greasy or strongly flavoured and try eating smaller, more frequent meals rather than large meals that may be harder to tackle.

Fatigue

This is the most common side effect of cancer treatment and is the feeling of extreme tiredness and a lack of energy. Doctors can prescribe medication to help patients deal with fatigue and research suggests remaining active can help. Feeling wiped out can be frustrating and make you feel a bit low, but try not to get down and continue to eat well and sleep often.

If you're experiencing fatigue, or having difficulties with day-to-day activities, an occupational therapist can work with you to provide solutions to this.

Low number of white blood cells

This is known as neutropenia. White blood cells are important in fighting infections, but these cells can be lowered during chemotherapy. To monitor this, patients may undergo numerous blood tests before, during and after chemotherapy.

Neutropenia is a more serious side effect of cancer treatment as it increases your risk of getting an infection.

A low number of platelets

A low number of platelets is known as thrombocytopenia. Platelets are cells which are made in the bone marrow and stop bleeding by helping to clot the blood. During chemotherapy treatment the number of platelets a person has in their blood can drop, which can lead to excessive bleeding, heavy nose-bleeds, severe headaches or dizziness.

Thrombocytopenia can be detected by a blood test, so it is important to tell your nurse if you experience these side effects as you may need your chemotherapy dose altering to manage this.

Mouth Sores

Mouth ulcers and a sore mouth and throat are common side effects of chemotherapy. Doctors can provide mouthwash and gels that can help and sucking ice cubes or eating ice cream can be soothing too! Continue to look after your teeth and gums – brushing carefully and using a soft brush.

> **“I had really bad mouth ulcers, but an ice cold pint of milk really worked for me and helped soothe them.”**
>
> **Former patient, aged 14 at diagnosis.**

Taste Changes

You may experience the taste of metal in your mouth or your favourite foods may suddenly taste bitter or salty. This will stop as soon as the chemotherapy does. It may help to use plastic cutlery or add herbs and spices to food to help with the flavour. If you want a bit more help with this, ask the dietician at your hospital for further advice.

Weight Loss or Gain

During treatment you may lose your appetite and begin to lose weight, or you may gain weight on certain treatments, such as steroids. Eating a nutritious diet and a variety of foods is important to help keep a stable weight and calories are really important, even if your mouth is sore! Your dietician will be a great help with this.

Many patients receiving chemo have trouble concentrating or remembering things. Your Step-By-Step Guide can help you with this. Use the notes pages (page 37 and 97) to keep track of conversations and your appointment tracker to plan your time. Writing on post-it notes or entering reminders to your phone can also help a lot.

Ask your key worker to talk you through the possible late effects of your treatment.

Long term side effects or late effects

The side effects we've mentioned so far will all stop once your treatment has finished. There is a chance that you may get some side effects from your treatment later on. However, this doesn't mean your cancer is returning.

Long-term side effects and late effects are slightly different, although often referred to as the same thing.

Long-term side effects may start during your treatment but can continue up until six months after your treatment has ended. These may be permanent or may just be side effects that take a little longer to go away.

Late effects on the other hand are a delayed response to treatment, and so begin after your treatment has finished, months or even years later.

These side effects vary greatly and depend on the treatment you received. Your medical team will inform you of all possible long-term and late effects before your treatment begins and if you have any uncertainties, just ask. It is also important to tell your medical team about any problems you're facing during regular check-ups after your treatment; this helps to pick up any effects as early as possible.

> **My daughter has at times been incredibly upset and down about the treatment she has endured. Fortunately, now the chemotherapy has finished, she seems to be returning to her former self and there don't appear to be any lasting emotional problems.**
>
> **Parent of female patient, aged 12 at diagnosis.**

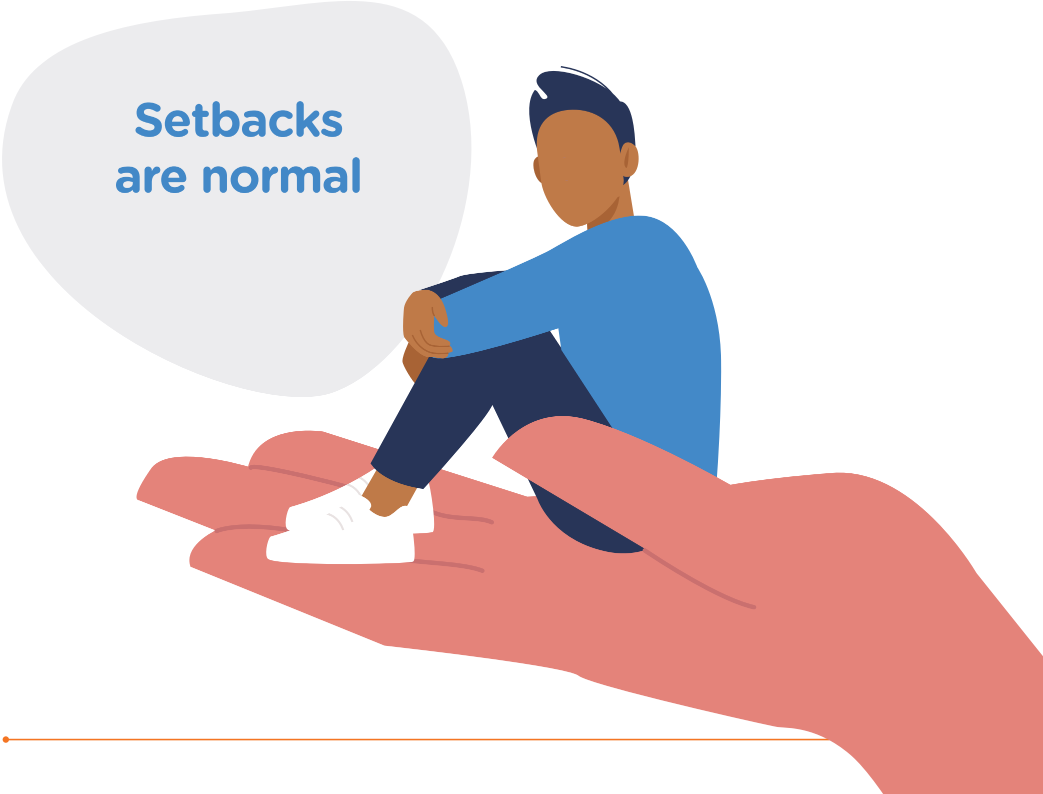
Setbacks during treatment

During your treatment, things may not always seem to be going to plan. Side effects from your treatment may be making you feel unwell, you may get an infection or you may have more surgery than you were expecting.

Try not to worry. All of these things are a normal part of cancer treatment and it does not mean that your treatment isn't working.

Try organising something fun to do when you feel up to it. A special treat, a day out with friends or a relaxing break can really help!

> **I feel older in a way, as I have been through more than most people my age could imagine. It changed my priorities in life and what I want to do with my life. I'm much more open to new opportunities and trying new things.**
>
> **Former patient, aged 21 at diagnosis.**



Pain management

Pain is both a symptom and a treatment side effect for many primary bone cancer patients and managing this pain is a crucial part of your care.

It is important to tell your medical team if you are in pain – they'll do their best to help.

You will receive plenty of assistance in managing your pain during this time. This may be through the use of anaesthetic during certain tests or surgical procedures, the use of painkillers or the use of other medications which can relieve bone pain; such as steroids or bisphosphonates.

Managing your pain

Medication to relieve your pain will be administered orally (by mouth) or intravenously.

Your pain may be constant, intermittent (meaning it comes and goes), or a combination of the two.

Some patients may feel anxious about speaking up about their pain. They don't want to cause a fuss or worry about the side effects of stronger pain relief - such as drowsiness.

It is important to remember that painkillers affect all patients differently and your medical team will control the dose you receive to help in reducing any drowsiness.

Recording when you experience pain, how it feels and what made the pain feel better or worse can help when discussing your pain with your medical team. Describing pain to your medical team on a scale of 0-10 (0 being no pain and 10 being extreme pain) can also help these discussions.

Pain clinics

Specialist Pain Clinics can provide both treatment advice and emotional support for patients suffering in pain. 'Pain Management Programmes' include group sessions to discuss and overcome the distress this causes.

Take your mind off it!

Anxiety and fear can actually increase the pain you are suffering from. Try to find ways to relax or distract yourself and don't be afraid to talk about how you're feeling with your friends, family or a professional.

Check out the British Pain Society for more information and advice about dealing with pain and finding your local pain clinic: britishpainsociety.org

Body image

Cancer and its treatment can change your body, your appearance or how your body functions.

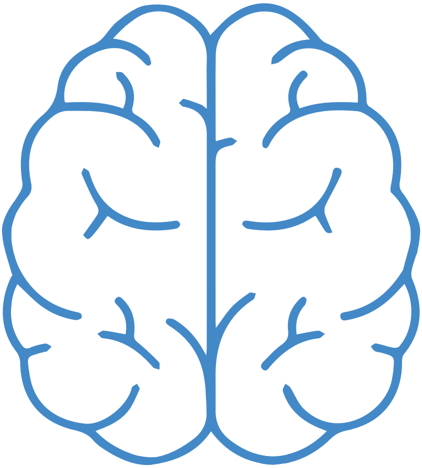
Some of these changes are temporary (such as hair loss) and others more permanent. Even those changes that aren't visible to others can affect how you feel about yourself.

Surgery can leave scars, a loss of sensation to an area or possibly a loss of part of your body. Not all of these changes may be negative! Some people have positive changes to their body or use this experience to learn a new level of appreciation for their body's strength and ability.

We really recommend talking to others who are going through, or have been through, a similar situation to yours. It'll help to hear how other people cope and learn that you are certainly not alone in this.

Even if you look or feel different, you are still the same person on the inside. Your personality, interests and talents aren't changed by cancer.

If there are certain hobbies or sports that you are unable to do, try finding a new activity you enjoy or learning a completely new skill to regain some confidence!



Remember your personality, interests and talents aren't changed by cancer

A healthy lifestyle

A balanced diet

Your diet seems like an odd thing to think about right now, but the side effects of chemotherapy can affect your appetite and cause you difficulties in eating, so it's important you're getting the right nutrients when you do feel up to eating.

Talking to a dietician at the hospital is the best thing to do; they can make sure you're getting the balanced diet you need to support your immune system during and after your treatment.

If you're finding it difficult to find the time or energy to get to the supermarket, try ordering your food shopping online to be delivered straight to your home

Staying active

Being active can give your body a boost. Many people say it's good for lifting your mood, helping with fatigue and strengthening your muscles and joints during treatment.

You don't need to push yourself though, if you're feeling wiped out, listen to your body.

Try a walk in the park to start and move on from there. This could be a great time to socialise with friends too!

Talk to a dietician for advice

Talking to other people who have been in a similar situation can really help.

Worries and concerns

Aside from your treatment and care, you may have some worries and concerns relating to personal aspects of your life. This is completely normal and a member of your medical team can sit with you to help you voice these concerns and provide you with the best information or support available.

Sometimes, it can be difficult to pinpoint these exact concerns and so your medical team will be able to provide you with a 'Concerns Checklist' to guide you to the areas you may wish to discuss further.

These may be:

Physical: Sleeping problems, exhaustion, pain, trouble with mobility or worries surrounding your body image.

Practical: Concerns regarding work or your education, seeking financial support or advice, requiring help with transport or more personal issues such as washing and dressing yourself.

Family or Relationships: You may have concerns for your partner, children, parents or friendships that you would like to discuss.

Emotional: You may wish to talk about a range of feelings, from anger and frustration to loneliness or fear.

Spiritual or Religious: Concerns regarding your faith and beliefs.

Lifestyle or Further Information: You may require advice on your diet and nutrition, continuing your hobbies, using complementary medicines or finding further support groups in your local area.

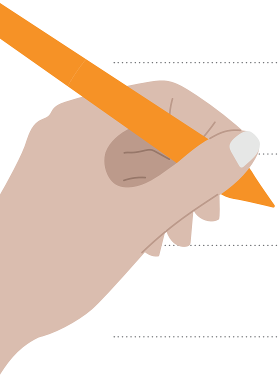
Whatever your concern, whether it is on the list of concerns provided to you or not, is worth voicing to a member of your medical team. They will be able to provide you with advice or information and find the most appropriate individual to help you further.

Some hospitals offer a 'Holistic Needs Assessment'. This is where you can 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. You may be offered an assessment around the time of diagnosis, during treatment or after treatment has ended. Be sure to ask about a 'Holistic Needs Assessment' in order to fully discuss the support you need.

Additional support

Once you have opened up these discussions with your clinical nurse specialist, key worker, social worker or other medical team member, you may be provided with extra information, contact details or additional services you can gain access to.

We have provided this page so you can note down these additional services, or perhaps make some notes on things that are playing on your mind if you're not quite ready to voice these.



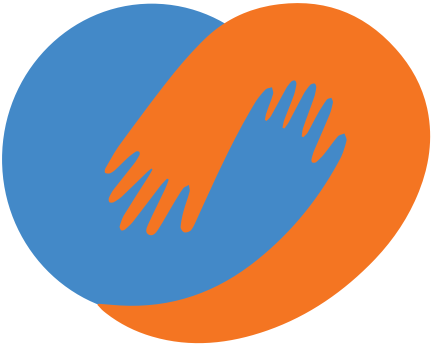
Getting the support you need

Your medical team will be familiar with some of the difficulties you and your family are facing. They will be able to provide help and advice.

The Bone Cancer Research Trust have a dedicated Support & Information Service, freely accessible to patients and their support networks. You can access this by email: **support@bcrt.org.uk**; phone: **0800 111 4855** and our website: **bcrt.org.uk/support**.

Talking to others

Talking to other people who have been in a similar situation can really help. The Bone Cancer Research Trust can put you in touch with other patients or family members who have faced similar challenges. Sarcoma support groups are another way to meet others in a relaxed environment.



Someone to call

There are many organisations that offer a support line to give advice on emotional and practical issues you may be facing.

Talking to an expert

Counselling may be an option for some patients and their friends and family members. Most GP centres and hospitals will have a trained counsellor they can arrange for you to meet on a one-to-one basis to discuss your feelings in a safe and confidential environment.

Don't be afraid to ask your medical team for more information on how you can access this help.

Support for Carers

It is important for carers to look after themselves too. The services mentioned on this page are also available to carers of people with primary bone cancer.

Try not to bottle up your emotions; it is essential for you to look after yourself as well at this time. For more guidance for carers, see page 86.

The bone cancer conference

Either on an annual or twice yearly basis we hold a 'Bone Cancer Conference' to bring together the entire bone cancer community.

Patients, former patients, family members, researchers, medical professionals – everyone working with or affected by primary bone cancer is welcome to join us.

The day is an excellent opportunity to learn more on the latest updates in bone cancer research, hear inspirational stories from those affected by this disease and meet other patients and families in an informal and supportive environment.

Email us at: **support@bcrt.org.uk**; visit **bcrt.org.uk/conference** to learn more on our next conference and register your attendance. Alternatively, you can call us on: **0800 111 4855**.

> You will surprise yourself at just how strong you can be. There will be times when you'll need a helping hand so don't be afraid to ask for one, no one is expecting you to face cancer on your own. Talk to someone about the way you are feeling and if like me it doesn't come easy, then keep a diary. It was a huge help throughout my diagnosis.
>
> Believe in yourself, have faith in your own ability and be proud of who you are and what you have achieved. You are capable of absolutely anything.

Nikky gibbons, former patient, aged 32 at diagnosis

Finances

Your clinical nurse specialist (or key worker) will be a great source of advice regarding finances. BCRT offers non-means tested grants to all newly diagnosed bone cancer patients, and to patients travelling for proton beam therapy or clinical trials. You can find out more information and how to apply at **bcrt.org.uk/support/financial-assistance-grants**

To give you an idea of what benefits are available to help cover the extra costs that come with cancer diagnosis we have listed some of the areas worth considering.

Organisations such as Macmillan Cancer Support and Young Lives vs Cancer have created excellent resources that explain the benefits you are entitled to and how to access them. They also offer one-off financial grants to help cover the costs associated with living with cancer.

Benefits surgery

Macmillan Cancer Support and the Citizens Advice Bureau have formed a partnership to provide advice to those affected by cancer.

This service helps with the paperwork involved in claiming benefits and can advise you on managing hospital costs. This service is easily accessible at Macmillan Information Centres and the Macmillan website.

Useful advice

- It is really important that you have **travel insurance**, but it can be hard to find a policy that suits you. **Cancer Research UK** provide a list of specialist insurance companies that have been recommended to them by patients.
- **Maggie's Centres**, which provide practical and social support to patients, are a great source of financial advice. Please see **bcrt.org.uk/support/our-support-groups-and-local-support-to-you/maggies-centres**.
- In the UK, cancer patients are entitled to **free prescriptions**. You will need to complete an FP92A form, which can be picked up at your GP or oncology clinic
- You can claim back the **cost of travel and parking** when attending hospital appointments. Visit the 'Hospital Cashier' for more help with this.

Give yourself time to adjust to emotional and physical changes.

For carers

Whether you're a parent, child, grandparent, sibling, partner or friend, having someone close to you who is diagnosed with cancer will affect you.

It's important to look after yourself during your time caring for someone else. It is understandable that you will have worries, may want to gain as much information as you possibly can and have concerns on handling family life.

It is important to share your concerns, speak to others in a similar situation and seek support and guidance from the medical team wherever you can.

Knowing what to say

One of the most challenging aspects can be knowing what to say during difficult times. Answering questions honestly is always best.

Speaking with the medical team, in particular a social worker or a clinical nurse specialist (often known as a 'key worker'), when you need advice on what to say or support for yourself will be a fantastic help.

Looking after yourself

It is very important to look after your own needs, and not feel guilty for doing so. Try find time to relax and socialise in between visits to take your mind off things.

Ensuring you are eating well, sleeping enough and taking regular breaks may be the last thing on your mind but it's important to take care of yourself.

Our guide for carers

- Try not to bottle up emotions; there are many people you can talk to about how you're feeling.
- Looking after yourself and taking care of your own needs is very important.
- Keeping your family and friends informed can help so they can offer you the support you need.
- Speak with your employer or GP if you need to arrange time off work or flexible working arrangements.

> **Take help when offered, your pride won't be dented and you'll actually make the person helping feel useful.**
> **Let them put the kettle on or hoover up.**
>
> **Former Osteosarcoma patient.**

We have put together a list of organisations that may be worth getting in touch with.

Handy contacts

At The Bone Cancer Research Trust, we have a dedicated Support & Information Service. You can contact us via email: **support@bcrt.org.uk** or via our freephone line **0800 111 4855**.

You could also have a look on our website, **bcrt.org.uk,** to find more information on primary bone cancer. Unfortunately, there are some areas of advice that we cannot provide or areas that other charities and organisations are much more experienced in handling.

For this reason, we have put together a list of organisations that may be worth getting in touch with.

Cancer Research UK

Provide information about cancer and coping with cancer.

Website: **cancerresearchuk.org**
Call: **0808 800 4040**

Carers UK

Offer information and support to carers across the UK. Their helpline is available in England, Scotland and Wales at:

Website: **carersuk.org**
Call: **0808 808 777**

Citizens Advice Bureau

Advice on legal issues, employment issues, financial matters and much more.

Website: **citizensadvice.org.uk**

Young Lives vs Cancer

Provide information and support for children and young people with cancer.

Website: **younglivesvscancer.org.uk**
Call: **0300 303 5220**

Children's Cancer and Leukaemia Group (CCLG)

Provide helpful information for young people with cancer and their families.

Website: **cclg.org.uk**
Call: **03330 507654**

Department for Work and Pensions

Advice on benefits for patients and their family members.

Website: **dwp.gov.uk**

Ellen Macarthur Cancer Trust

A national charity that rebuilds confidence after cancer using sailing as a support to empower young people aged 8-24 years of age.

Website: ellenmacarthurcancertrust.org
Call: 01983 297750

Irish Cancer Society

A national charity providing a range of cancer information and support services.

Website: cancer.ie
Call: 1800 200 700

Macmillan Cancer Support

Provides practical, medical and financial support for cancer patients and their loved ones.

Website: macmillan.org.uk
Call: 0808 239 0843

NHS Choices

Provide health information to help you make the best choices about your health and lifestyle, as well as making the most of NHS and social care services in England

Website: nhs.uk

Samaritans

Offer a 24 listening service for anybody needing someone to talk to.

Website: samaritans.org.uk
Call: 116 123

Sarcoma UK

Raise awareness of sarcoma and provide support.

Website: sarcoma.org.uk
Call: 0808 801 0401

The 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

Shine Cancer Support

A network for anyone living with cancer in their 20's, 30's or 40's. Providing social events, workshops and support.

Website: shinecancersupport.org

Teenage Cancer Trust

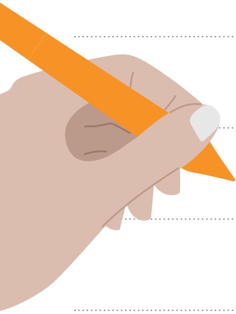
A charity dedicated to improving the lives of teenagers and young adults with cancer.

Website: **teenagecancertrust.org**

Our '**Handy Contacts**' list provides the information of just some of the organisations you may find helpful. You can find more organisations on our website at **bcrt.org.uk/support**.

It is likely that you will come across many more fantastic organisations aside from our list. Your medical team will be able to advise you on organisations and local support groups that you may also benefit from. If you wish, you can use the space below to write down any additional contacts you want to keep!

If you think any other contacts should be added to our 'Handy Contacts' we would love to hear about them, please pop them in an email to **support@bcrt.org.uk** or give us a call on **0800 111 4855.**



Jargon buster

You'll probably hear a lot of new words once you've been diagnosed with cancer, and although your medical team will try explaining everything to you as clearly as possibly, you're likely to hear a few words that you don't understand. You shouldn't be afraid to ask your team what certain words you hear or read mean, but we have provided a glossary in case you need a reminder.

If you've heard or seen a word that we don't have in this glossary, please let us know by emailing **support@bcrt.org.uk** so we can add it in the future!

A

Adjuvant: treatment applied after an initial form of treatment. For example adjuvant chemotherapy is administered after surgery.

Alopecia: the medical name for hair loss.

Amputation: removal of a limb due to a trauma or disease.

Anaemia: a lower than normal level of red blood cells in the blood; this can leave you feeling worn out or dizzy.

Anaesthetic: medicine used during tests and surgical procedures to numb certain areas of the body or induce sleep to prevent pain or discomfort.

Analgesic: the medical name for a painkiller.

Antiemetics: drugs that stop patients from feeling nauseous or being sick.

Asymptomatic: a condition or disease which produces no symptoms.

Autograft: replacing tissue from one part of a patient's body using tissue from another area of their body

B

Benign: a mass of cells that is not cancerous. These tumours grow in one place and do not spread.

Biobank: a collection of anonymised patient samples and clinical data stored for use in research.

Biopsy: a small sample of tissue that is taken so a doctor, known as a pathologist, can look closely at the cells making up the tumour and run tests on the sample.

C

Cancer: a disease caused by abnormal and uncontrolled growth and division of cells.

Cannula: a flexible tube inserted into a blood vessel in the lower arm or hand to give medicine or an anaesthetic.

Central Line: a long, flexible, tube that goes into the central blood vessel in the chest. This is used to give medicines, fluid or to take blood from a patient.

Chemotherapy: A treatment for cancer that uses one or more medicines to kill cancer cells.

Chemoresistant: when a certain cancer type, or specific patients' tumour, does not respond to chemotherapy.

Cisplatin: a chemotherapy drug that is given to primary bone cancer patients. Cisplatin works by binding (or sticking) to DNA to cause the cell to die.

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

Curettage: a method of surgery which removes the tumour by scraping or scooping the cancerous cells away.

Cyclophosphamide: a chemotherapy drug that is given to primary bone cancer patients. This drug is known as an ‘alkylating agent’ and it slows down the growth of cancer cells.

Cytotoxic: drugs that are toxic to cancer cells and cause them to die

D

Dexamethasone: a steroid drug which decreases inflammation. Dexamethasone may be used to manage some of the side effects caused by cancer treatment.

Diagnostic: the techniques and procedures used to diagnose a disease.

DNA: stands for deoxyribonucleic acid. This is present in all living organisms and carries the genetic material of a cell.

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

Eligibility Criteria: certain requirements that an individual must meet in order to take part in a clinical trial.

Endoprosthesis: an artificial implant used to replace part of the body that is missing; ‘endo’ means ‘inside’.

Enneking System: a staging system of musculoskeletal tumours to classify tumours in order to determine the best way to treat them

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 kills the cancer cells.

F

Fatigue: the medical definition for extreme tiredness caused by a disease .

Femur: the bone in the upper leg, also known as the thighbone.

Fibula: the smaller, outer, bone of the leg between the knee and the ankle, also referred to as the calf bone.

Follow-Up: care given after finishing treatment to check for medical issues that may arise months or years after treatment has finished .

G

G-CSF: short for granulocyte colony stimulating factor. A growth factor that stimulates the bone marrow to produce white blood cells.

Genes: 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.

H

Hickman Line: a long, flexible, tube that goes into a vein in the chest. This is used to give medicines, fluid or to take blood from a patient.

High-Dose Chemotherapy: cancer treatment using very high doses of chemotherapy drugs to kill cancer cells.

Holistic Needs Assessment (HNA): An assessment and discussion you may have with someone from your healthcare team. Together, you talk through your needs and concerns. You then agree on a plan for your care and support needs..

Humerus: the bone of the upper arm which forms joints at the shoulder and the elbow.

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.

Incidence: the rate at which a disease is occurring, or the frequency of a disease.

Infertile (infertility): the inability to have children. Infertility can be a side effect of cancer treatment Intensity-Modulated.

Radiotherapy (IMRT): an advanced form of radiotherapy that uses computerised planning to deliver the radiation to the tumour with little effect to surrounding tissues.

Intermittent Pain: a term used to describe pain which comes and goes.

Intravenous (IV): simply means ‘within the veins’ and this is one of the best ways to administer treatment and fluids as it is a quick route of delivery to the body.

L

Late effects: problems that patients may develop after cancer treatment, these can occur months or even years after treatment has finished.

Lesion: an area of a tissue that has suffered damage; this may be from injury or disease and may range from a wound to a tumour.

Limb-Sparing 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.

Liver Function Tests (LFT’s): a blood test which gives information on the functioning of a patient’s liver. This is a useful test for determining the body’s reaction to treatment.

Localised Cancer: cancer that has not spread to other areas of the body.

M

Malignant: tumours that are cancerous and have the ability to spread.

Metastasis: the spread of cancer to another area of the body to form a secondary tumour. Primary bone cancer can spread to the lungs or to other bones.

Methotrexate: a chemotherapy drug that is given to primary bone cancer patients to slow down the growth of cancer cells by interfering with the production of the cell’s DNA.

Metoclopramide (Maxolon): a drug used to treat nausea and vomiting, which may be a side effect of chemotherapy.

Mifamurtide (Mepact): A treatment for osteosarcoma patients between 2 and 30 years, it can be given to patients after surgery alongside chemotherapy.

Multi-Disciplinary Team (MDT): a team made up of various healthcare professionals with differing skills and areas of expertise. An MDT work together to ensure each patient receives the best possible treatment plan.

N

Nausea: the feeling of sickness and needing to vomit.

Neo-Adjuvant: treatment carried out before the main treatment procedure. For example, neo-adjuvant chemotherapy aims to shrink the tumour to allow an easier surgical procedure to follow.

Neutropenia: a low count of white blood cells, known as neutrophils, in the blood. This is often caused by chemotherapy and affects the immune-system; increasing a patient's risk of infection.

O

Ondansetron: a drug used to treat or prevent nausea and vomited associated with cancer treatment.

Orthopaedic: the branch of medicine specialising in the bone and muscles.

Orthotist: a specialist who provides aids for people with nerve, muscle or bone disorders. These aids include special footwear.

Osteoblast: cells which specialise in making bone. They work alongside osteoclasts to constantly remodel and reshape the bone.

Osteoclast: cells which breakdown the bone. They work alongside osteoblasts to constantly remodel and reshape the bone.

Outcome: the result of a disease that directly affect the length or quality of a patient's life.

Outpatient: attending hospital for treatment without needing to stay overnight. Some radiotherapy or chemotherapy may be given in outpatients.

P

Paediatrician: a doctor who specialises in treating children.

Palliative: treatment used to help support patients and to manage or relieve their symptoms to improve their quality of life.

PEG: also known as a Percutaneous Endoscopic Gastrostomy: is used to get nutrients and fluids directly into a patient's stomach if they are unable to eat or swallow.

PICC Line: a long, flexible, tube that goes into a vein in the arm, leg or neck. This is used to give medicines, fluid or to take blood from a patient.

Portacath: a thin, flexible, tube inserted into a blood vessel in the chest then connected to a small box which lies under the skin. This small box is used to give medicines, fluid or to take blood from a patient.

Primary Tumour Site: the site where the cancer originated and developed.

Prognosis: the long-term outlook of a disease in terms of survival and recovery.

Promethazine: a drug used to treat allergic reactions or act as a sedative to induce calm and sleepiness.

Prosthetic: an artificial limb designed to replace a missing part of the body.

Prosthetist: a specialist who designs and creates artificial limbs for individuals.

Proton Beam Therapy: an advanced form of radiotherapy. Unlike conventional radiotherapy, proton beam therapy stops once it “hits” the cancerous cells; resulting in much less damage to surrounding tissues.

R

Radiotherapy: a form of cancer treatment that uses high-energy x-rays to damage and destroy cancer cells.

Radius: one of two bones making up the lower arm. It runs from the thumb to the elbow.

Reconstruction: surgery carried out following the removal of the tumour to restore the functioning and appearance of the affected area of the body.

Recurrence or Relapse: cancer returning at a later date after treatment has finished.

Referral: the transfer of a patient’s care from one medical professional to another.

Regimen: a plan of the medicines that a patient will have. The regimen will inform all carers of the treatment plan, the dose and how long and how often it will be given for.

Rehabilitation (Rehab): a specialised form of care that is carried out after treatment. Rehab, which may include physiotherapy and/or occupational therapy, allows the patient to return to normal life and regain their strength and independence.

Remission: when the signs or symptoms of cancer have disappeared a patient is in remission.

S

Sarcoma: cancer that forms in the connective tissues of the body; such as the bone, muscles, nerves or fat. Primary bone cancer is also known as bone sarcoma.

Second Opinion: getting the view of a medical professional who has not previously been involved in a patient’s care.

Side Effects: undesirable effects to healthy areas of the body caused by treatment.

Stem Cell: cells capable of developing into many different types of cell, they act as a repair system to replace cells.

Stem Cell Harvest: a procedure used to collect stem cells from a patient in order to store them and return them at a later date. This is carried out so that any blood cells destroyed by chemotherapy can be replaced with these stem cells during a stem cell transplant.

T

Terminal: a word used to describe a disease, such as cancer, which cannot be cured.

Tibia: the larger, inner, bone of the leg between the knee and the ankle; also referred to as the shin bone.

Tissue: consists of specialised cells which form areas of the body to carry out a specific function

Topotecan: a chemotherapy drug that is given to primary bone cancer patients. This drug works by stopping an enzyme known as Topoisomerase I from working, which leads to damaged DNA and the cancer cell being destroyed.

Treatment Cycles: a cycle includes the treatment time, which may be 3-4 days plus a rest period for the body to recover.

Tumour: is a swelling or lump caused by the abnormal growth and mass of cells. Tumours can be benign (non-cancerous) or malignant (cancerous).

Tumour Grade: a way of classifying the tumour. It assesses how abnormal the cells of the tumour appear, how different the tumour is to a healthy tissue and how quickly the cells are dividing. High grade tumours are often more aggressive.

Tumour Marker: a substance produced by a tumour which can be found in the blood and help doctors to understand how the tumour is behaving.

Tumour Stage: a way of describing how big the tumour is and whether or not it has spread to neighbouring tissues or other areas of the body.

U

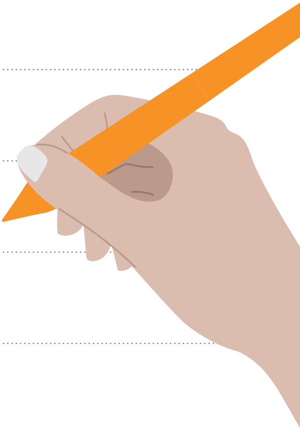
Us & Es: short for urea and electrolytes; is a type of blood test to examine the levels of waste products in the blood. This can give clues as to how well the kidneys are working.

W

White Blood Cells: blood cells which are part of the immune system and therefore help the body to fight off infections and disease.

If you've heard a word we don't mention, let us know at support@bcrt.org.uk.

Notes



Thank yous

This ‘Step-By-Step Guide’ was written and published by the **Bone Cancer Research Trust**, who are committed to providing reliable, accurate and trustworthy information.

Information provided in the guide should be used in conjunction with the advice and information provided to you by a healthcare professional with knowledge of your circumstances. This guide should not be used as a replacement for talking to your medical team.

We would like to say a huge thank you to everyone involved in the development of this resource; from oncologists, nurses and surgeons to parents, patients and everyone in between forming our voluntary Information Advisory Panel (IAP). Our special thanks to: Gill Johnston, Malcolm Matthews, Richard Moody, Philippa Large, Jane Forsythe, Anita Pabla, Vicky Wren, Peter Lloyd, Nikky Gibbons, Gita Patel, Andrew Westwood, Imogen Westwood, Mark Vincent & Val Matthews.

Author: Hannah Birkett
(Previous Research and Information Officer at The Bone Cancer Research Trust).

Design: Matt Thompson
The Bone Cancer Research Trust

If you have any queries on the production of this resource or the sources used to create it, have any comments on its content or wish to join our voluntary panel of information reviewers please get in touch with us at **support@bcrt.org.uk** or call us on **0800 111 4855**

A little more about us

The Bone Cancer Research Trust (BCRT) is the leading charity dedicated to fighting primary bone cancer. Our mission is to save lives and improve outcomes for people affected by primary bone cancer through research, information, awareness and support.

Our ambition is for a future where primary bone cancer is cured. For those affected by the disease right now, our high-quality information and supportive network means no-one should have to feel alone or isolated.

The Bone Cancer Research Trust relies entirely on voluntary donations to continue our work - we receive no governmental funding. To find out more about us, how we can help you or the pioneering research we fund.

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

@BCRT
/BoneCancerResearchTrust
@bonecancerresearch

V1.0: SEPT 23

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

@BCRT
/BoneCancerResearchTrust
Bone Cancer Research Trust
@bonecancerresearchtrust
@bonecancerresearch

10 Feast Field, Horsforth, Leeds LS18 4TJ

Registered charity in England & Wales: 1159590

Review dates for this booklet:
Version 4 produced: 07/08/23
Next review of booklet due: 07/08/26

BONE CANCER RESEARCH TRUST