Key points about

PRIMARY BONE CANCER

Trusted Information Creator

Patient Information Forum

BONE CANCER RESEARCH TRUST

Who this booklet is for

This booklet has been written for patients, their families, friends and the general public. It is to help them understand more about primary bone cancer, its symptoms, how it is diagnosed and treated.

What primary bone cancer is

Primary bone cancer is the name given to cancer that starts in a bone. It is a rare type of cancer that can develop in any bone in the body. Primary bone cancer is sometimes called a 'bone sarcoma'.

Sarcoma is the name given to a cancer that starts in the 'connective tissue'. This includes bones and their surrounding cartilage, and soft tissues, such as muscle and fat.

The most common place for it to start is in the lower limbs (legs), such as the thigh bone (femur) or shin bone (tibia). This is followed by the hip (pelvis) and the bones of the upper limbs (arms), such as the humerus.

Every year, around 560 people in the UK will be told they have primary bone cancer. This is the same as around 10 people each week.

Who primary bone cancer affects

Primary bone cancer affects people of all ages. It is seen most often in people aged 10 to 25 years old and over 50 years old. Males are at a slightly higher risk of getting some types of primary bone cancer than females.

Symptoms of primary bone cancer

Symptoms of primary bone cancer can vary depending on its size and where it is in the body. Symptoms may be quite general and can be similar to other conditions. They may be mild at first and slowly get worse, or they may suddenly appear. The type and extent of symptoms will be different for every person.

Symptoms include:

- bone pain which might be worse at night, happens all the time or stops and starts, is not helped by painkillers and the pain may get worse over time
- a lump or swelling, which may be seen or felt if the tumour is near the skin's surface. Called a 'palpable mass'
- problems moving, may develop a limp, stiff limbs or joints, unable to move as normal
- tenderness over the bone or joint
- a broken bone caused by weakening of bone due to a tumour, without having had a fall or accident. Called a 'pathological fracture'

Other possible symptoms are:

- a high temperature (fever), feeling tired or weary ('lethargy' or 'fatigue'), pain with tingling and numbness ('pins and needles'), bruising easily, weight loss and loss of appetite, sweats at night, feeling breathless

Types of primary bone cancer

The 4 most common types of primary bone cancer are:

- Chondrosarcoma: **bcrt.org.uk/chondrosarcoma**
- Ewing sarcoma: **bcrt.org.uk/ewingsarcoma**
- Osteosarcoma: **bcrt.org.uk/osteosarcoma**
- Chordoma: **bcrt.org.uk/chordoma**

Other rarer types of primary bone cancer are:

- Spindle Cell Sarcoma of the Bone: **bcrt.org.uk/spindlecellsarcoma**
- Adamantinoma: **bcrt.org.uk/adamantinoma**
- Angiosarcoma of the Bone: **bcrt.org.uk/angiosarcoma**
- Giant Cell Tumour of the Bone: A usually non-cancerous (benign) tumour: **bcrt.org.uk/giantcelltumour**

Causes of primary bone cancer

Doctors and scientists do not yet know exactly what causes primary bone cancer or how to stop it happening.

We do know that:

- Some 'genetic conditions' or 'syndromes' increase the risk of you getting primary bone cancers.
- You cannot catch it from anyone else.
- It is not caused by something you have done or not done.

Diagnosing primary bone cancer

Primary bone cancers are very rare, and some GPs (general practitioners) will never come across them. This means they are often misdiagnosed. You might need to visit a doctor more than once before you are sent for more tests ('referred') and get a diagnosis.

If a primary bone cancer or bone tumour is suspected, you will be referred to a specialist bone cancer centre. Doctors will carry out different tests before a diagnosis of primary bone cancer can be confirmed.

These tests may include:

- X-ray (usually carried out first)
- Biopsy (where a small piece of tumour is collected and the cells are looked at under a microscope and genetic testing may be carried out)
- Blood tests
- CT scan, MRI scan, PET scan
- Bone scan
- Bone marrow biopsy

These tests help your doctor work out the:

- **Grade** of cancer (grade 1 to 3): How quickly it might grow and spread.
- **Stage** of cancer (stage 1 to 4): How big it is and if it has spread from the original site to other parts of the body.

Understanding the stage and grade of the cancer means your doctor can choose the best treatment options for you. They will talk to you about how they are going to grade and stage the cancer.

Whole genome sequencing

You may be asked to give a blood and tissue sample for whole genome sequencing, to the National Genomic Research Library. To find out more, visit Genomics England's webpage: **genomicsengland.co.uk**

Holistic Needs Assessment

This is where you have a chat with someone in your medical team who will ask you questions about your worries and concerns. It covers all parts of life. They will work with you to create a support plan. You may be offered an assessment at diagnosis, during treatment or after treatment.

Prognosis

When a person has an illness, doctors try to predict how it will affect that person. For example, how likely it is that the treatment will work, and the person will be cured. This is called a 'prognosis'. Doctors will look at your general health, the type of tumour and whether it has spread anywhere else in the body to make a prognosis for primary bone cancer. Everyone is different, so doctors can never be sure how primary bone cancers will affect each person.

Treatments for primary bone cancer

Treatments for primary bone cancer include:

- surgery
- radiotherapy (including proton beam therapy)
- chemotherapy (before and after surgery, or if the cancer comes back)

Your treatment plan will be individual to you. It will depend on the type of primary bone cancer and where it is in the body. This means someone else may have a similar cancer but may not have the same treatment.

You will have some different tests, such as blood, hearing, heart and kidney tests before and during treatment. These tests are to check if the treatment is suitable, and to check for side effects.

Cancer treatments can also affect fertility (the ability to have children). The effect on your fertility will often not be known until after your treatment has finished. Talk to your doctor, clinical nurse specialist (CNS) or key worker before treatment starts. There may be ways to preserve your fertility if you want to have children in the future.

Where you will be treated

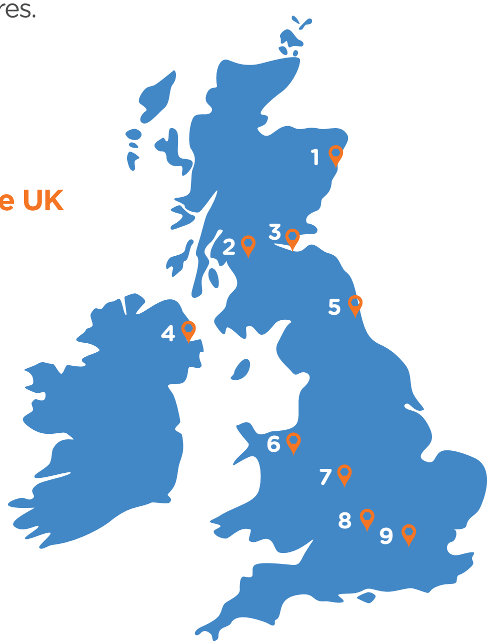
Where you are treated will depend on things such as the type of primary bone cancer you have, your age and where the cancer is in the body. Most people are usually diagnosed and usually have surgery at a specialist bone cancer centre.

There are 9 specialist bone cancer centres across the UK, in Aberdeen, Belfast, Birmingham, Edinburgh, Glasgow, London, Newcastle, Oswestry, Oxford.

Chemotherapy and radiotherapy may take place at a bone cancer centre across the country or a different hospital closer to you. Your medical team will talk to you about this. Children and young people are treated in specialist centres.

Bone cancer centres in the UK

1. Aberdeen
2. Glasgow
3. Edinburgh
4. Belfast
5. Newcastle
6. Oswestry
7. Birmingham
8. Oxford
9. London



Who will treat you

You will be treated by a team of people who are experts in bone cancer. These people will include oncologists (a doctor who cares for people with cancer), surgeons, nurses, including a clinical nurse specialist (CNS), radiologists, social workers, support workers, dieticians, physiotherapists and many others. This group is called a 'multi-disciplinary team' (MDT). The MDT will plan and decide on what treatment and care is best for you, with your input.

Each person with primary bone cancer is given a CNS, sometimes called a 'key worker'. They are there throughout treatment to give support and listen to questions or worries you may have.

Support after treatment

The end of your treatment will come as a welcome relief, but it can also be a time of worry and anxiety.

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

The Bone Cancer Research Trust's Support and Information Team can connect you with others who have experience of primary bone cancer. You can also find patient stories on our website at: **bcrt.org.uk/patientstories**

There are lots of other organisations who can support you too. They are listed on our website at: **bcrt.org.uk/usefulorganisations**

Follow-up care

Your doctors will want to monitor you for a long time after treatment (called 'follow-up care'). Outpatient hospital visits will be needed, the frequency of these will depend on each person.

Doctors will check your general health, talk about any worries you may have and do tests to:

- check if the cancer has come back (called 'relapse' or 'recurrence')
- check for any 'late effects' from the cancer treatment

You may also have follow-up care with a surgical team. In-between visits, it is important you get in touch with your clinical nurse specialist (CNS) or doctor straight away if you have any problems.

Rehabilitation

During and after treatment, many people benefit from 'rehabilitation' ('rehab'). This is a form of therapy that helps people regain strength and manage day-to-day activities.

At the start of rehab, you will be given advice, and maybe some exercises to do. These are to improve your strength, fitness and ability to move around on your own, or in a wheelchair.

The BCRT has some support and information videos about rehab which you may want to watch. Find them on our website at: **bcrt.org.uk/support/webinars**

Late effects

Most people will have side effects during treatment. These effects may go away or get better after treatment ends. However, some become permanent or start after treatment ends. These are called 'late effects' of cancer treatment. Not everyone will get late effects and they may vary in each person.

Talk to your doctor or clinical nurse specialist (CNS) about possible late effects of your treatment. They will be able to tell you more about the support available.

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The Bone Cancer Research Trust
The Bone Cancer Research Trust (BCRT) is the leading charity dedicated to fighting primary bone cancer. We are here for anyone who needs information on, or support with, primary bone cancer. You can also find a list of questions to ask your medical team on our webpage: **bcrt.org.uk/aboutpbc**

For more information about primary bone cancer, the references used to create this booklet, or if you have any questions or feedback, contact our Support and Information Service:

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

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Visit **bcrt.org.uk/ourhealthinformation** to find out how we produce our information resources and to read our disclaimer.

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