Key points about
CHONDROSARCOMA

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Patient Information Forum



BONE CANCER RESEARCH TRUST

Who this booklet is for

This booklet is written for people affected by primary bone cancer. It is to help you understand key points about chondrosarcoma, its symptoms, diagnosis, and treatment.

You can also visit our website for more information: **bcrt.org.uk/chondrosarcoma**

What chondrosarcoma is

Chondrosarcoma is a type of primary bone cancer (also called 'bone sarcoma' or 'tumour'). Each year in the UK, around 219 people are diagnosed with chondrosarcoma.

Sarcoma is the name given to a cancer that starts in the 'connective tissue'. This includes bones, muscles, fat and other soft tissues. Chondrosarcoma is a tumour which starts from cells that make cartilage.

Chondrosarcoma can start from any bone. The most common places that chondrosarcoma starts are the:

- pelvis
- ribs
- leg (thigh bone or shin bone)
- upper arm ('humerus')
- shoulder blades

In rare cases, chondrosarcomas can also be found in the spine, skull, or soft tissue near the bones.

Who chondrosarcoma affects

- Overall, chondrosarcoma is the most common type of primary bone cancer.
- It makes up around 1 in 3 of all primary bone cancers diagnosed in the UK.
- It is the most common type of primary bone cancer in adults. Children are less likely to develop chondrosarcoma.
- It is more common in people over 20 years old. It makes up around half of all primary bone cancer cases in people aged 50 to 59.
- In high grade chondrosarcoma, women have better outcomes than men. This is because oestrogen has a protective effect. After the age of 55 (post-menopause), this effect is not seen.

Symptoms of chondrosarcoma

Chondrosarcoma can cause a wide range of symptoms. They may be mild at first and slowly progress, or they may suddenly appear. The symptoms and number of symptoms vary for every person.

Symptoms may 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. This may be called a 'palpable mass'
- a broken bone caused by weakening of bone due to a tumour, without having had a fall or accident. This is called a 'pathological fracture'
- problems moving, may develop a limp, stiff limbs or joints, unable to move as normal
- feeling tired or weary ('lethargy' or 'fatigue'), pain with weakness, tingling and numbness ('pins and needles'), weight loss and loss of appetite
- if the tumour is on the spine, muscle spasms or muscle weakness

Types of chondrosarcoma

Chondrosarcomas can be classified into:

- **Conventional chondrosarcoma:** Out of all chondrosarcoma cases, around 8 to 9 in every 10 people will be diagnosed with conventional chondrosarcoma.
- **Dedifferentiated chondrosarcoma:** This is a rare chondrosarcoma.
- **Mesenchymal chondrosarcoma:** This is a rare chondrosarcoma.
- **Clear cell chondrosarcoma:** This is a rare chondrosarcoma.

Causes and risk factors of chondrosarcoma

There has been a lot of research into possible causes of chondrosarcoma, but this is still not fully understood. Researchers have found a pair of genes, called '*IDH1*' and '*IDH2*', in chondrosarcoma tumours that are often damaged ('mutated').

The chances of getting chondrosarcoma are slightly increased if you have:

- bone disease, such as enchondroma, Ollier disease or Maffucci syndrome
- conditions passed on from your parents, such as multiple osteochondromas, sometimes called 'Hereditary multiple exostoses'
- had radiotherapy in the past

Diagnosing chondrosarcoma

Doctors will carry out several different tests before a diagnosis of chondrosarcoma can be made. These tests may include:

- X-ray, usually carried out first
- blood tests
- CT scan, MRI scan, PET scan
- a biopsy, where doctors collect a small piece of tumour and look at the cells under a microscope

X-rays and scans help doctors to see the size of the tumour and exactly where in the body it is. Scans also check if the cancer has spread to any other parts of the body. This is called 'staging'. Using the test results, the doctor will decide on a treatment plan.

Holistic Needs Assessment

You may be offered a 'Holistic Needs Assessment' at diagnosis, during treatment or after treatment. This is where you have a chat with someone in your medical team. They 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.

If your hospital does not offer a Holistic Needs Assessment, you can still talk to your medical team about any worries or concerns you have. They are there to help.

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 how likely it is that the person will be cured. This is called a 'prognosis'. Doctors will consider lots of things about you and the tumour when making a prognosis. Everyone is different, so doctors can never be sure how chondrosarcoma will affect each person.

Treatments for chondrosarcoma

Most people are usually diagnosed and usually have surgery at a bone cancer centre. Each person will have their own treatment plan.

The most successful treatment for chondrosarcoma is surgery. radiotherapy, Proton Beam Therapy (PBT), or chemotherapy may also be used in a small number of cases.

Surgery

The aim of surgery is to completely remove the primary tumour and keep the body working as normally as possible. This is to stop the tumour from growing back again.

Most people who have surgery will have a 'wide resection'. This involves removing the affected area of bone and healthy tissue around the tumour. This maximises the chance of removing all the cancer cells.

Other types of surgery are sometimes used to treat chondrosarcoma. Your medical team will talk to you about the best type of surgery for you.

Chemotherapy, radiotherapy and Proton Beam Therapy (PBT)

Chemotherapy, radiotherapy and PBT are used less often to treat chondrosarcoma because they are not very effective. However, they may be considered for some types of chondrosarcoma.

Some people with chondrosarcoma may be eligible for PBT. This is a type of high dose radiotherapy that is less likely to damage healthy tissue around the tumour.

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 other people 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. This is 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 concerns and do tests to:

- check if the cancer has come back (called 'relapse' or 'recurrence'), often with a chest X-ray
- check for any 'late effects' from the cancer treatment. Find out more about late effects on our webpage: **bcrt.org.uk/information/long-term-and-late-effects-resources/**

You may also have follow-up care with a surgical team.

In-between visits, it is important you get in touch with your key worker or doctor straight away if you have any problems or concerns.

If chondrosarcoma comes back

Sadly, chondrosarcoma can come back in some people. If the cancer does return, you may have more surgery, or possibly, radiotherapy or chemotherapy. You may be asked to take part in a clinical trial. Treatments will depend on each person. The doctors and nurses will talk you through the treatment options in detail.

Advanced chondrosarcoma

Your doctor may have told you that the cancer can no longer be cured. The focus now is to make you comfortable and give you as much time as possible with your loved ones. They may talk to you about palliative care, ways to ensure your pain is managed and hospice care. For more information on this, contact our Support and Information Team.



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Also available: Our website.
Visit: **bcrt.org.uk/chondrosarcoma**

For more information about 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
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