Information for healthcare professionals

CHONDROSARCOMA

Trusted Information Creator

Patient Information Forum



BONE CANCER RESEARCH TRUST

This information has been written for healthcare professionals to help raise awareness of chondrosarcoma, its symptoms, diagnosis and treatment.

The following Bone Cancer Research Trust (BCRT) chondrosarcoma resources are available for patients:

- Key points about chondrosarcoma: A leaflet providing a summary of information.
- Our chondrosarcoma webpage: **bcrt.org.uk/chondrosarcoma**

To request copies of the above, please:

Call: 0800 111 4855

Visit: bcrt.org.uk/requestinformation

Email: support@bcrt.org.uk

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What chondrosarcoma is and who it affects

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, known as 'chondroid tissue' (but not from cartilage that lines the bony joints, like the knee or hip). Cartilage is a rigid, flexible connective tissue, often found in the joints.

Chondrosarcoma usually forms in the bone and can develop anywhere in the skeleton.

The most common places that chondrosarcoma can start are in the:

- pelvis
- legs (proximal femur in the thigh and tibia in the shin)
- upper arms (humerus)
- ribs
- shoulder blades

In rare cases, chondrosarcomas can also develop in:

- the spine or base of the skull
- soft tissue near the bones (ligaments, tendons, muscles and fat), where it is referred to as an 'extra-skeletal chondrosarcoma'

Who chondrosarcoma affects

- Overall, chondrosarcoma is the most common type of primary bone cancer (of all grades).
- It accounts for 33% of all primary bone cancer cases 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 due to the protective effect of oestrogen. After the age of 55 (post-menopause), this effect is not seen.

Symptoms of chondrosarcoma

The symptoms of chondrosarcoma are non-specific and can be similar to some other conditions (see 'Alternative diagnoses' section below).

Symptoms may:

- be mild at first and slowly progress, or they may start suddenly
- vary for every patient and can present alone or in combination with other symptoms
- differ depending on the location of the tumour in the body

Some chondrosarcomas may be painless. Sometimes, people may have a test for a symptom not related to chondrosarcoma and the tumour is detected at the same time. Or, the tumour may only be found when a person breaks a bone in a fall or accident, or if the bone has been weakened by the tumour. People may also develop symptoms when the original tumour has spread to other parts of the body.

Common symptoms of chondrosarcoma include:

- bone pain, which may:
  - be worse at night
  - be constant or intermittent
  - be resistant to analgesia
  - increase in intensity over time
- bony or soft tissue swelling / masses
- pathological fractures
- mobility issues such as an unexplained limp, joint stiffness or reduced range of motion (ROM)

Other possible symptoms may include:

- lethargy or fatigue (feeling tired or weary)
- pain with weakness, tingling and numbness ('pins and needles') in limbs
- weight loss and loss of appetite
- muscle spasms, tingling or weakness, if the tumour is on the spine

People with spinal chondrosarcoma have neurological symptoms. These may include pain, numbness or tingling, problems with passing urine or opening bowels, muscle spasms and muscle weakness. Chondrosarcoma in the base of the skull can also cause neurological symptoms.

Types of chondrosarcoma

Chondrosarcomas belong to a group of tumours called ‘chondrogenic bone tumours’. These chondrogenic bone tumours may be:

- malignant tumours, which can spread to other parts of the body
- non-cancerous (benign) tumours

The table below shows the different types of chondrogenic bone tumour in each category:

Benign (n=8)	Malignant (n=7)
Subungual exostosis	Chondrosarcoma, grade 1/ACT
Bizarre parosteal osteochondromatous proliferation	Chondrosarcoma, grade 2
Periosteal chondroma	Chondrosarcoma, grade 3
Enchondroma	Periosteal chondrosarcoma
Osteochondroma	Clear cell chondrosarcoma
Chondroblastoma	Mesenchymal chondrosarcoma
Chondromyxoid fibroma	Dedifferentiated chondrosarcoma
Osteochondromyxoma	

Types of chondrosarcoma

Malignant chondrosarcoma tumours, including ACTs, chondrosarcoma grade 1 and chondrosarcoma grades 2 and 3, may be central or secondary peripheral. These are shown in the table below:

8 sub-types of chondrosarcoma (including atypical cartilaginous tumours (ACTs))

	Chondrosarcoma sub-type
Conventional chondrosarcoma (n=5)	Central atypical cartilaginous tumour (ACT) in the limbs / Central chondrosarcoma grade 1 in the pelvis, scapulae and skull base
	Secondary peripheral ACT/ chondrosarcoma grade 1
	Central chondrosarcoma grades 2 and 3
	Secondary peripheral chondrosarcoma grades 2 and 3
	Periosteal chondrosarcoma
Rarer sub-types (n=3)	Dedifferentiated chondrosarcoma
	Mesenchymal chondrosarcoma
	Clear cell chondrosarcoma

Secondary chondrosarcomas develop from an existing benign bone tumour.

Most chondrosarcomas grow slowly and do not spread quickly. The type and grade will determine the likelihood of metastasis. The most common sites for metastases are the lungs.

Types of chondrosarcoma

Conventional chondrosarcoma:

- Makes up around 80 to 90% of all chondrosarcoma cases.
- Is a slow-growing tumour.
- Most commonly affects adults over 50 years old.
- Affects slightly more males than females.
- Conventional chondrosarcomas can be further classified based on how they look and where in the bone they started. Patients may sometimes have a biopsy and imaging scans as part of their diagnosis.
- Most people have low grade conventional chondrosarcomas. They are either atypical cartilaginous tumours (ACTs) or chondrosarcoma grade 1 (CS1), depending on their location. Around 85 to 90 in every 100 conventional chondrosarcomas are grade 1 tumours or ACTs.
- In rarer cases, conventional chondrosarcomas can be grade 2 or 3 (high grade). Low grade tumours are less aggressive and easier to treat.
- Most start inside the bone ('central'), however, a small number start on the bone surface, known as 'periosteal chondrosarcoma'.
- They can affect any bone, but the pelvis and upper thigh bone (proximal femur) are most commonly affected. They may also be found in the upper arm bone (humerus), lower thigh bone (distal femur), ribs, scapulae and, less commonly, the spine and base of the skull.

Dedifferentiated chondrosarcoma:

- Makes up around 10% of all chondrosarcoma cases.
- Is a fast-growing tumour.
- It is usually diagnosed in older adults between the ages of 50 to 70 years old. The average age at diagnosis is 60 years old.
- As well as grade 1 to 2 chondrosarcoma cells, these tumours contain other types of high grade sarcoma cells, similar to other high grade bone tumours, such as osteosarcoma. It is therefore high grade and aggressive.
- Most commonly starts in the thigh bone (femur) or pelvis.

Types of chondrosarcoma

Clear cell chondrosarcoma:

- Makes up around 2% of all chondrosarcoma cases.
- Is a slow-growing tumour.
- Is more likely to affect adults aged between 20 and 50 years old.
- Affects more males than females.
- Is low grade.
- Often starts in the long bones of the arms or legs.
- Is called clear cell chondrosarcoma because the inside of the cells appear clear.

Mesenchymal chondrosarcoma:

- Makes up around 2 to 4% of all chondrosarcoma cases.
- Is a fast-growing tumour.
- Is more likely to affect teenagers and young adults.
- Is very aggressive.
- Can start anywhere in the body. Around 70% of mesenchymal chondrosarcomas start in the bone and 30% in soft tissue outside the bone (extra-skeletal). In the bones, mesenchymal chondrosarcoma is most common in the jaw and ribs.
- Cells of mesenchymal chondrosarcoma may resemble cells of Ewing sarcoma, a type of primary bone cancer. It can therefore sometimes be misdiagnosed.

Identifying the sub-type of chondrosarcoma allows for the best treatment plan to be developed for each individual patient. It is important not to confuse chondrosarcoma with chondroblastic osteosarcoma. The treatments for each are different.

Causes of chondrosarcoma

The actual cause of chondrosarcoma is not yet fully understood. Research has shown a pair of genes ('*IDH1*' and '*IDH2*') are often mutated in chondrosarcoma tumours and some other cancer types too, such as brain tumours. The cause of mutation is unknown, but we do know that it is not inherited.

Risk factors of chondrosarcoma

Some risk factors have been identified which may increase an individual's risk of developing a chondrosarcoma. These risk factors include:

- **Previous radiotherapy treatment in the same area**
- **Existing bone disease:**
  - **Enchondroma:** A benign bone tumour that begins in cartilage
  - **Ollier disease:** A condition in which benign bone tumours cause expansion and deformity in the affected bones. It usually starts in children and young adults under 20 years old. People with Ollier disease have up to a 50% chance of developing chondrosarcoma, but this will depend on the pattern and extent of the tumours. Many people with Ollier disease have mutations in *IDH1* or *IDH2* genes
  - **Maffucci syndrome:** This is a very similar condition to Ollier disease, causing multiple expansions and deformities of bone. People with Maffucci syndrome have around a 50% chance of developing chondrosarcoma. Many people with Maffucci syndrome have mutations in *IDH1* or *IDH2* genes
- **Inherited risk factors:**
  - **Multiple osteochondromas, sometimes called hereditary multiple exostoses (HME):** This is a genetic condition that can be passed down to a child from a parent. In some cases, it can be caused by a genetic mutation that happens spontaneously at any time in life. The condition causes bone growths called 'osteochondromas' or 'exostoses'. People with multiple osteochondromas have a small risk of developing chondrosarcoma (between 0.5 to 5%)

Diagnosing chondrosarcoma

The symptoms of chondrosarcoma are non-specific. There is no single clear sign that doctors can easily look for to make a diagnosis. Primary bone tumours are rare and many GPs will have very little or no experience of them.

If a GP is worried about a person's symptoms, they should follow:

- **The National Institute for Clinical Excellence (NICE) guidelines for suspected bone cancer and other sarcomas**
- **The National Institute for Clinical Excellence (NICE) guidelines for Suspected cancer: recognition and referral**
- **The British Sarcoma Group's UK guidelines for the management of bone sarcomas**

As per the NICE guidelines, the first step in diagnosis involves a clinical examination and an X-ray. It should be done from 2 different angles (in 2 planes) to get a good image of the bone. Further tests will then be carried out to confirm a diagnosis of chondrosarcoma. They **may** include:

- blood tests
- CT scan
- MRI scan
- PET scan
- biopsy of the suspected tumour

Imaging helps 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'.

Taking a biopsy involves taking a small sample of the tumour and examining it under a microscope. However, it is not always indicated for chondrosarcoma. Results from a biopsy can take up to 2 weeks to analyse.

Doctors use all the test results to confirm the presence and type of chondrosarcoma and decide on a treatment plan.

Patients may be asked to donate a tissue sample for research (tissue banking) and whole genome sequencing, to contribute to the National Genomic Research Library. By taking part, it may help:

- the patient's clinical team get answers which could lead to a diagnosis, access to a different treatment, or an opportunity to participate in clinical trials
- identify whether the parents of the patient have passed on a predisposition to cancer
- other sarcoma patients and more widely, other cancer patients in the future
- researchers to understand sarcomas better, to improve things for patients now or, more likely, in the future

To find out more, visit Genomics England's webpage: **genomicsengland.co.uk**

Diagnosing chondrosarcoma

Alternative diagnoses

When diagnosing chondrosarcoma, it is important to consider other health conditions or more common illnesses, which may present in a similar way. These conditions include:

- **Benign tumours of bone:** such as enchondroma or osteochondroma
- **Secondary bone tumours:** cancer which has spread to the bones from elsewhere in the body. Most commonly to the breast, prostate, bronchus, kidney and thyroid
- **Ewing sarcoma:** a type of primary bone cancer. When viewed under the microscope, Ewing sarcoma cells may resemble the cells of mesenchymal chondrosarcoma. Visit **bcrt.org.uk/ewingsarcoma** for more information

Holistic Needs Assessment

Patients, their family or friends may benefit from discussing any feelings of anxiety or their concerns. Some hospitals offer a 'Holistic Needs Assessment' for patients. This is where they can have a chat with someone in their medical team who will ask questions about their worries and concerns. It covers all parts of life, not just how cancer and treatments affect the body.

A support plan will be made to help the patient manage their worries and concerns. Patients can ask their medical team for more information about this. They may be offered an assessment around the time of diagnosis, during treatment or after treatment has ended.

Prognosis

'5-year survival' in chondrosarcoma is around 80%. This means, overall, around 80 in every 100 people with chondrosarcoma are alive 5 years after diagnosis but some may still be having treatment. However, this statistic is highly dependent on the grade of the tumour. 5-year survival rates are estimated to be over 93% for grade 1 tumours, 74% for grade 2 tumours and 31% for grade 3 tumours.

Other factors, such as the tumour location, the type of chondrosarcoma and whether it is metastatic also affect survival. For example, dedifferentiated chondrosarcoma is a sub-type with a poorer prognosis, with an estimated 5-year survival rate between 10% and 13%.

Healthcare professionals should consider the following when making a prognosis for chondrosarcoma:

- where in the body the tumour is. This can affect which treatments will work best
- the size of the tumour
- the age and general health of the person
- if the chondrosarcoma is at the primary site, or is metastatic
- the type of chondrosarcoma, as some are more aggressive
- the grade of the tumour
- whether the tumour can be fully removed with surgery

Because everyone is different, doctors can never be sure how chondrosarcoma will affect an individual.

Treatments for chondrosarcoma

Most patients will usually be diagnosed and usually have surgery at a bone cancer centre.

The most effective treatment for chondrosarcoma is surgery. In a small number of cases, radiotherapy, proton beam therapy (PBT) or chemotherapy may be used.

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 ('local recurrence'). The type of surgery a patient has will depend on:

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

It is very difficult to remove the tumour in some people. For example, if it is in the pelvis or spine.

If the cancer has spread, the secondary tumours may also be removed by surgery.

Surgery for atypical cartilage tumour (ACT) low grade chondrosarcomas

ACTs / low grade chondrosarcomas can be treated using different surgical procedures:

- **Wide resection:** The affected area of bone is removed along with healthy bone and tissue around the tumour to ensure complete removal
- **Curettage:** Tumour cells are scraped out of the bone
- **Cryosurgery:** Following curettage, remaining cancer cells may be frozen using liquid nitrogen
- **High-speed burring:** Following curettage, remaining cancer cells may be destroyed using a small tool that rotates quickly inside the bone

If the bone needs to be rebuilt, surgery may include:

- **Allograft:** The affected area of bone is removed and bone donated by another person is used to reconstruct the bone
- **Autograft or autologous graft:** The affected area of bone is removed and replaced with healthy bone and tissue from another area of the patient's body
- **Endoprosthetic replacement:** The affected area of bone is removed and replaced with a metal prosthesis

Treatments for chondrosarcoma

Surgery for high grade chondrosarcoma

High grade chondrosarcomas can be treated using wide resection. The affected area of bone is removed along with healthy bone and tissue around the tumour to ensure complete removal.

For some high grade chondrosarcomas, it may be possible in some parts of the body to remove the tumour without needing to rebuild the bone.

High grade chondrosarcomas, such as dedifferentiated or mesenchymal chondrosarcomas, are more likely to be metastatic. This means other treatments like radiotherapy, proton beam therapy (PBT) or chemotherapy may be used but this is rare.

Limb-sparing surgery

If the chondrosarcoma is in a limb the medical team will attempt to save the limb by doing limb-sparing surgery. The whole tumour is removed and the space left is replaced with a piece of bone from another part of the body, or from another person, or using a metal implant:

- **Endoprosthetic replacement:** Following removal of the tumour, the area of damaged bone is replaced with a metal implant (an 'endoprosthesis'). If the tumour is near a joint, it may also be replaced. This is a common technique for primary bone cancers of the arms, legs, shoulders and pelvis
- **Allograft:** The affected area of bone is removed and bone donated by another person is used to reconstruct the affected bone
- **Autograft or autologous graft:** The affected area of bone is removed and replaced with healthy bone and tissue from another area of the person's body

Patients undergoing limb-sparing surgery will need some rehabilitation soon afterwards. They will speak with a physiotherapist and in some cases an occupational therapist, before and, or after surgery.

Amputation

In some cases, removal of the whole limb is needed.

An amputation may be needed if the tumour:

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

If possible, a prosthetic limb will be made for the patient. Information about amputation can be found on BCRT's website at: **bcrt.org.uk/amputation**

Other types of treatment

Radiotherapy

Radiotherapy means treating the tumour with high doses of concentrated radiation. It is not a very effective treatment for most people with chondrosarcoma. However, in rarer cases, it may be used:

- as a potential treatment for some cases of high grade chondrosarcomas, such as mesenchymal or dedifferentiated chondrosarcoma
- to reduce pain and discomfort when cancer is advanced and cannot be cured, known as 'palliative radiotherapy'

Proton Beam Therapy (PBT)

Some patients with chondrosarcoma may be eligible for PBT. For example:

- when a tumour is close to the base of the skull, spinal cord or nerves
- as a treatment for high grade chondrosarcomas, such as mesenchymal or dedifferentiated chondrosarcoma

PBT is a type of radiotherapy that delivers a radiation dose directly to the tumour. This means healthy tissue around the tumour is less likely to be affected. In the UK, PBT is only available at The Christie Hospital, Manchester and at University College London Hospital, London.

Cases will need to go to a PBT panel, which will decide if a patient is eligible. Applications for PBT must be made using the NHS Proton Beam Therapy Referral Portal: **protons.protontherapyreferrals.nhs.uk/login**

If patients are eligible for PBT, the BCRT offer financial assistance to support the extra costs associated with travel and hospital stays. Patients can find out more about our Financial Assistance Grants here: **bcrt.org.uk/support**

Chemotherapy

Pre- or post-operative chemotherapy is not used for most people with localised chondrosarcoma. This is because conventional chondrosarcoma does not usually respond to chemotherapy. There is limited evidence which supports the use of pre- or post-operative chemotherapy for mesenchymal and dedifferentiated chondrosarcoma.

Research shows chemotherapy has limited benefit for metastatic chondrosarcoma.

After treatment

Follow-up care

When treatment is finished, doctors will monitor patients for a long time. This is called follow-up care. Outpatient hospital visits will be needed. The frequency of visits will depend on the patient. It might be every 3 months for the first 2 years after finishing treatment, every 6 months in years 3, 4 and 5, then annually after that.

At these visits, doctors check a patient's general health, discuss concerns and run tests to:

- check for relapse or recurrence (if the cancer has come back), including a chest X-ray
- check for any 'late effects' from the cancer treatment. This includes longer-term effects on kidney function, fertility and risk of developing secondary cancer

Patients may also have follow-up care, where their surgical team will look out for any surgery-related problems. If the patient has a new limb, they will also make sure the limb is working well.

These visits can also be useful for patients to talk about any emotional or practical worries or problems they may have.

In-between visits, it is important that patients report any problems or concerns to their medical team.

Rehabilitation

During and after treatment, many patients benefit from rehabilitation. A therapy that helps them regain strength and tackle day-to-day activities.

Rehabilitation services include:

- **Physiotherapists:** Help patients return to an active lifestyle, restoring strength, movement and function.
- **Occupational therapists:** Help improve patients' ability to do everyday tasks.
- **Dieticians:** Offer advice on suitable nutrition during and after treatment.
- **Prosthetists:** Design and create prostheses for patients who have had amputations, matching as closely as possible to the affected limb.
- **Orthotists:** provide aids for patients who have had surgery, such as splints or special footwear.

The BCRT has a selection of Support and Information Webinars which might be helpful for patients to watch during rehabilitation: **bcrt.org.uk/support/webinars**

After treatment

Advanced chondrosarcoma

A patient's cancer may come back (recur), at which point, their medical team will decide on the best course of action. This might include further surgery, other treatments or deciding whether a clinical trial may be beneficial (if available), or supportive care. This decision will be made by the patient with their treating clinician.

The patient may be told that the cancer can no longer be cured and the focus now is to make them comfortable and give them as much time as possible with their loved ones.

The hospital team may talk to the patient about palliative care and ways to ensure their pain is managed. They may also talk to them about hospice care. The team could help direct patients to a local hospice or patients might like to search for one themselves.

Support after treatment

Patients may be worried about their cancer coming back. They may also feel lost and alone or worried about leaving behind the medical team and support network at the hospital. Parents or carers may also feel like this.

Services are available which offer support. These include:

- **Psychological support and services:** Psychologists will support patients with any concerns, feelings of anxiety or depression.
- **Local support groups:** Many support groups are organised and run locally. Clinical nurse specialists can usually provide information on local services.
- **The Bone Cancer Research Trust (BCRT):** Provides support and information for people affected by primary bone cancer. The BCRT can connect patients with others who have experience of primary bone cancer.
- **Macmillan Cancer Care:** Provide useful information for adults who have had treatment for cancer, and who are living with and beyond cancer.
- **Other charitable organisations:** There are lots of charities that provide support and information. See our 'Other useful organisations' webpage for details: **bcrt.org.uk/support/other-useful-organisations**

The Bone Cancer Research Trust (BCRT)

The BCRT is a leading charity dedicated to fighting primary bone cancer. We are here for anyone who needs information on, or support with, primary bone cancer.

As well as producing information for patients, we offer a range of primary bone cancer information resources and training for healthcare professionals. Visit our website to find out more:
bcrt.org.uk/information/for-healthcare-professionals

You can also visit **bcrt.org.uk/ourhealthinformation** to find out how we produce our health information resources.

Contact our Support and Information Service:

Call: 0800 111 4855
(Monday to Friday, 9am to 5pm)
Email: support@bcrt.org.uk
Visit: bcrt.org.uk/support

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Your feedback

We are always trying to improve our information. If you would like to share any thoughts about this resource, please get in touch. Your feedback helps us to make sure our current resources meet your needs and helps with the development of new resources.

Visit our website: bcrt.org.uk/contact

Email: support@bcrt.org.uk

Call: 0800 111 4855



References

The Bone Cancer Research Trust's information has been created using peer reviewed clinical and scientific publications, reviews, case studies and reference books. If you are interested in reading more, below is a list of key references used to compile our information about chondrosarcoma.

For a full list of references and further reading, or for more information, contact our Support and Information Service. You can also visit our Request Information Materials webpage to order printed resources for patients: **bcrt.org.uk/requestinformation**

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