Information for healthcare professionals

GIANT CELL TUMOUR OF THE BONE

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Patient Information Forum

BONE CANCER RESEARCH TRUST

This information has been written for healthcare professionals to help raise awareness of Giant Cell Tumour of the Bone, its symptoms, diagnosis and treatment.

The following Bone Cancer Research Trust (BCRT) Giant Cell Tumour of the Bone resources are available for patients:

- Key points about Giant Cell Tumour of the Bone: A booklet providing a summary of information.
- Our Giant Cell Tumour of the Bone webpage: **bcrt.org.uk/giantcelltumour**

To request copies of the above, please:
Call: 0800 111 4855
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What Giant Cell Tumour of the Bone is

Giant Cell Tumours of the Bone are usually not cancerous, but they can be locally aggressive. This means they can grow quickly and destroy surrounding bone and soft tissue.

Giant Cell Tumours of the Bone make up to 5 in every 100 **primary bone tumours** worldwide.

This type of tumour usually develops next to the joints in the long bones of the body. For example, in the:

- thigh bone (femur)
- shin bone (tibia)
- lower arm bone (radius)

The most common place this tumour develops is around the knee. Around half of Giant Cell Tumours start here.

Giant Cell Tumours of the Bone are named based on how they look under a microscope. Many individual cells join to create a single large cell or 'giant cell'.

Who Giant Cell Tumour of the Bone affects

Giant Cell Tumour of the Bone affects one to two people in every million, each year worldwide.

Most of these tumours affect people between 20 and 45 years of age. Giant Cell Tumours of the Bone can also affect children and older people, but this is rare.

We do not yet know why this tumour is more likely to affect people in Southern India and China. In these locations, Giant Cell Tumours of the Bone make up 20 in 100 primary bone tumours compared with up to 5 in 100 worldwide.

Symptoms

The symptoms of Giant Cell Tumours of the Bone 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 Giant Cell Tumours of the Bone may be painless. Sometimes, when people have no symptoms, a routine test not related to the tumour may pick up on it. 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, and the doctor picks up on these symptoms.

Common symptoms of Giant Cell Tumour of the Bone include:

- bone pain
- swelling
- a lump, with or without pain
- tenderness over the bone or joint
- loss of function or mobility in the affected limb
- a change to the look or feel of the joint
- a build-up of fluid in the joint near the tumour
- a broken bone caused by weakening of the bone due to a tumour, without having had a fall or accident. This is called a 'pathological fracture'

The location and size of the tumour may affect the symptoms patients have. Tumours which develop on the spine, particularly in the sacrum (base of the spine where it connects to the pelvis), can lead to:

- back pain
- neurological effects, such as weakness or numbness in the arms and legs, a sensation of pins and needles

Causes

The cause of Giant Cell Tumour of the Bone is not known. In rare cases, Giant Cell Tumour of the Bone may develop as a complication of Paget's disease of the bone. More information about Paget's disease can be found on the **Paget's Association website**.

Diagnosing

The symptoms of Giant Cell Tumours of the Bone are non-specific. There is no one clear sign that doctors can easily look for to make a diagnosis. Primary bone tumours are very 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 Giant Cell Tumour of the Bone. These may include:

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

Imaging helps doctors to see the size of the tumour and exactly where in the body it is.

A biopsy involves taking a small sample of the tumour and examining it under a microscope. Results from a biopsy can take up to 2 weeks to analyse. Doctors use all the test results to confirm a diagnosis of Giant Cell Tumour and decide on a treatment plan.

Alternative diagnoses

Even with a biopsy, it can be difficult to correctly diagnose Giant Cell Tumour of the Bone. This is because giant cells are found in other tumours, or other areas of the body which do not have a tumour. This means other possible health conditions must be ruled out before diagnosing Giant Cell Tumour of the Bone.

Other conditions which can present in a similar way to Giant Cell Tumour of the Bone include:

- **Giant cell-rich osteosarcoma (GCRO)**: A type of osteosarcoma which has many giant cells making up a tumour.
- **Aneurysmal bone cysts (ABCs)**: A cyst which is blood-filled and not cancerous (benign). It can start in any bone in the body, causing pain and can fracture the bone.
- **Brown tumours**: A rare tumour which is not cancerous (benign). It looks similar to Giant Cell Tumours on imaging tests and under the microscope.

Holistic Needs Assessment

Patients 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. They will ask questions about their worries and concerns. It covers all parts of life, not just how the tumour 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

Healthcare professionals will consider the following when making a prognosis for Giant Cell Tumour of the Bone:

- where in the body the tumour is, since this can affect which treatments will work best
- the size and grade of the tumour
- the age and general health of the patient
- how the tumour responds to treatment

Because everyone is different, doctors can never be sure how Giant Cell Tumour of the Bone will affect each patient.

Treatments

The most common treatment for Giant Cell Tumour of the Bone is surgery. Targeted drug therapy, such as denosumab, may sometimes be used. In rare cases, chemotherapy and radiotherapy may be used.

Surgery

Most patients will usually have surgery at a bone cancer centre. These are special centres where a group of experts will discuss and manage patient care together.

Since Giant Cell Tumours of the Bone often develop near the joints, the main aim of treatment is to:

- remove the tumour to reduce the risk of it returning
- maintain the function of the bone and how it looks as far as possible

The 2 types of surgery which may be used to remove the tumour are:

Curettage surgery

Curettage surgery involves scraping out the tumour cells from the affected area, to create a hole. The surgeon may then fill the hole with bone cement or a bone graft to help make the bone stronger and to try and prevent the tumour coming back.

Wide surgical excision or resection

If the tumour is aggressive and has damaged a lot of the bone, the patient may have more invasive surgery. This involves taking 'wide surgical margins', where the tumour is removed along with some healthy tissue. The affected bone is reconstructed using bone grafts or a metal implant. This type of surgery can lower the risk of the tumour returning but may have a larger impact on the patient's cosmetic appearance and bone function. This means it is usually only used for more aggressive Giant Cell Tumours or Giant Cell Tumours of the Bone which return.

Targeted drug therapy

There is ongoing research into the development of 'targeted drug therapy' for Giant Cell Tumour of the Bone. A targeted drug called 'denosumab' may be used. Denosumab has been found to work well to control Giant Cell Tumour of the Bone. It works by stopping the tumour from dissolving the surrounding bone.

Denosumab is sometimes used:

- before surgery to improve the surgical removal of the tumour
- in cases where Giant Cell Tumour of the Bone cannot be removed with surgery
- in cases where surgery would be disabling

When a patient is given denosumab, they will have regular X-rays to check how the drug is affecting the tumour. Doctors will decide on the best time to operate.

More information about denosumab and its possible side effects can be found on the **Royal Orthopaedic Hospital's website.**

Radiotherapy

Radiotherapy is only used in rare cases. It involves treating the tumour with high doses of concentrated radiation. It may be used for Giant Cell Tumours of the Bone which cannot be removed by surgery.

Radiotherapy can increase the risk of a non-cancerous and less aggressive Giant Cell Tumour turning into a cancerous (malignant) tumour in the future. This is called 'radiation-induced sarcoma'.

Malignant transformation of Giant Cell Tumour of the Bone

Giant Cell Tumours of the Bone are not usually cancerous. But in very rare cases, Giant Cell Tumours can be cancerous (malignant) at diagnosis, or if they return ('recurrence'). They may also become cancerous after treatment, such as radiotherapy. This is called 'primary and secondary malignant Giant Cell Tumour of the Bone'.

- Primary malignant giant tumours of the bone make up around 2 in every 100 cases of Giant Cell Tumours of the Bone.
- Secondary malignant giant tumours of the bone make up around 2 in every 100 cases of Giant Cell Tumours of the Bone.

There are cases where cancerous tumours like osteosarcoma, fibrosarcoma or malignant fibrous histiocytoma have developed from Giant Cell Tumour of the Bone treated with radiotherapy.

The transformation of a non-cancerous Giant Cell Tumour of the Bone into a cancerous Giant Cell Tumour can happen up to 20 years after initial treatment. This shows how important surgery is to remove all the tumour, so there is less risk of it returning.

Chemotherapy (chemo)

Currently, chemotherapy (chemo) is not an effective treatment for Giant Cell Tumour of the Bone. It is instead used to treat malignant Giant Cell Tumour of the Bone.

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 on a regular basis. The frequency of visits will depend on the patient. It might be every 3 months for the first 2 years after finishing treatment, then every 6 months in years 3, 4 and 5. If the tumour comes back, a patient will have follow-up care for a total of 10 years.

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

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

A chest X-ray and X-ray of the site of the tumour will be taken at each visit. Patients may also have follow-up care, where their surgical team will look out for any surgery-related problems.

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 they experience 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 a patients' ability to do everyday tasks
- **Dieticians:** Offer advice on suitable nutrition for patients during and after treatment
- **Prosthetists:** Design and create prostheses for patients who have had amputations, matching as closely as possible to the patients' affected limb
- **Orthotists:** Provide aids for patients who have had surgery, such as splints or special footwear

If Giant Cell Tumour of the Bone comes back

The outcome for people with **Giant Cell Tumour of the Bone is generally positive**, provided the tumour is controlled by treatment. If controlled, there is less risk of it returning.

If Giant Cell Tumour of the Bone comes back in the same area as the original tumour, this is called a 'local recurrence'. The recommended treatment may be more aggressive than before.

Giant Cell Tumours can spread to other parts of the body, usually the lungs. This is called 'metastasis'. It can affect up to 7 in every 100 people with Giant Cell Tumours. Further treatment for this may be surgery or denosumab.

The Bone Cancer Research Trust (BCRT)

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

As well as producing information for patients, we offer a range of primary bone cancer and tumour 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**
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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 references used to compile our information about Giant Cell Tumours of the Bone.

You can also visit our Request Information Materials page to order printed resources for patients: **bcrt.org.uk/requestinformation**

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V1.0: FEB 25

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Key points leaflet about Giant Cell Tumour of the Bone.

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Review dates for this booklet:
Version 1 produced: 02/25
Next review of booklet due: 02/28

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