



The bone & soft tissue cancer charity

Giant cell tumours of the bone

What is GCT?

Giant cell tumours (GCT) are benign (non-cancerous) tumours that develop in the bone. They mostly occur in the long bones found in the arms and legs. They are always found at the end of the bone next to the joint. Although they are benign, GCT can grow fast and damage the affected bone and spread to the soft tissue around it. GCT mostly affects people between the ages of 20 and 30 years old. It is also more common in women. We do not know why they arise.

Signs and symptoms

The most common symptoms of GCT are:

- Pain
- Swelling in the area of the tumour
- Fractures in the bone caused by bone weakness

Who will treat me?

People with a suspected GCT should be referred to a specialist sarcoma team for diagnosis and treatment. There are five national bone sarcoma centres in England and Wales where all bone sarcoma patients should be treated. These are located in Newcastle, Manchester & Oswestry, Birmingham, Oxford and London. People in Northern Ireland will be treated in Belfast. People in Scotland will

be treated in Glasgow, Edinburgh, Aberdeen, Dundee and Inverness. As there are only a small number of centres that treat GCT, you may have to travel some distance for your treatment.

Some treatments like radiotherapy or chemotherapy may be given in your local hospital under the supervision of the specialist sarcoma centre.

Your case will be managed by a team of experts from a wide range of health care professions called a multidisciplinary team (MDT). Your MDT will include your key worker or sarcoma clinical nurse specialist, surgeon and other healthcare professionals involved in your care.

How is GCT diagnosed?

A specialist doctor will diagnose GCT through a series of tests. These may include:

- Physical examination
- A scan – taking pictures of the inside of the body using x-ray, bone scan, CT or MRI
- A biopsy – taking and testing a tissue sample

You may also have a chest x ray to look for any cells that may have spread to the lungs. This is extremely rare in GCT patients.

What treatment is available?

The treatment you receive will depend on a number of factors including:

- The size of your tumour
- Where it is in your body
- Whether it has spread to another part of your body
- Your general health and wellbeing

Your doctor or clinical nurse specialist will talk you through your options so you can decide together what the best choice is for you.

Surgery

Usually, the first treatment option for GCT is surgery. The aim is to clean out the GCT from the involved bone and then to carefully check that no GCT cells are left behind. This procedure is known as curettage.

The surgeon will then use a substance to try and ensure any remaining GCT cells are killed off. The most common substance used is bone cement. It is used to fill the cavity left behind when the GCT was removed. This gives immediate support for the cavity as it sets very quickly, usually in 13 minutes. It also gives off heat when it sets which helps kill off any GCT cells that may have been left behind.

A large variety of substances have been used to treat GCT, including phenol and liquid nitrogen, but there is no proof that any one is better than the other.

The affected bone can often be quite weakened by the GCT, so structural support is often needed to strengthen the bone. This can be provided by bone cement as mentioned above or by using a bone graft.

Bone grafts involve taking out the affected bone and replacing it with bone from another part of the body or an artificial bone substitute. Bone grafts do not have the advantage of killing off tumour cells like cement does. However, if your

surgeon is sure that they have cleaned out all the GCT or if bone cement is not appropriate then a bone graft may be used.

Sometimes the GCT can destroy a lot of the bone and sometimes the bone is already broken. In this case your surgeon may advise that the safest option is to remove the entire area of affected bone. This will almost always involve the removal of the end of the long bone and will frequently mean that an artificial joint replacement will be needed. This will usually be a specially designed joint replacement like those used for bone sarcoma patients.

What are the advantages and disadvantages of these procedures?

The advantage of a curettage, with or without cement or bone graft, is that you get you keep your own joint. The disadvantage is the risk of the tumour coming back. This can be as high as 30%.

The advantage of surgery to remove the affected bone area is that the whole GCT is removed and there is a very low risk, less than 5%, of it coming back. The disadvantage is that you will probably need an artificial joint replacement. This will never restore you to normal function and will be at risk of problems in the future such as infection, coming loose and wearing out.

In many situations the surgeon will try curettage as the more conservative option. If that does not work then surgery with reconstruction will be used.

Biological therapy

Biological therapies are treatments that interfere with the way cells work. Denosumab is the biological therapy that is sometimes used to treat GCT.

GCT is caused by giant cells that work like osteoclast cells. These are the cells that are

normally present in the body to break down old bone. GCT cells produce overenthusiastic osteoclasts that break down healthy bone cells and destroy the bone. Denosumab works by controlling the activity of osteoclast cells. It is used to stop bone damage in people who have GCT of the bone and it can be used to shrink a GCT enough so it can be removed safely through surgery.

Most people will start to find that any pain they have reduces within a few weeks of Denosumab treatment. X-rays and scans will show the GCT shrink a bit, then bone will start to reform at the edges of the cavity within a few months.

Increasingly, Denosumab is being used to try and shrink a GCT so it can be removed safely through surgery. This would involve a short course of treatment for 3-6 months. This may mean a smaller operation can be done, for example, curettage rather than surgically removing the affected bone.

What are the side effects of Denosumab?

Denosumab was originally used to treat GCTs in places where they could never be surgically removed or where surgery would be disabling, like the spine, skull or pelvis. Denosumab has proved very effective, but there are increased concerns that it may have long term side effects. These include:

- Osteonecrosis of the jaw – damage to the jaw leading to deep ulcers
- Atypical stress fractures of the long bone – pain in the long bones with activity

After treatment

After treatment for GCT, you will have regular follow-up appointments for several years. You should receive a follow-up schedule from your clinical nurse specialist.

The usual practice will include:

- a chance to discuss symptoms

- an examination to look for any signs of the tumour returning. This may include an x-ray or MRI if required

What if my GCT comes back?

GCT is known to come back in the same area of the original tumour. This is called a local recurrence. If the tumour does reappear, it is important to get treated as quickly as possible. This could involve further surgery or Denosumab treatment. Your treatment will be assessed on an individual basis.

You can check for recurrences yourself through self-examination. The most common sign of a GCT recurrence is pain. You may also find a new swelling or a lump. If you are worried about your tumour returning, contact your doctor or nurse. They may decide to bring forward the date of your follow up appointment to investigate your concerns.

What if my GCT spreads to another part of my body?

A recurrence of GCT can rarely be accompanied by GCT cells in other parts of the body. This is called metastasis. This is very rare for GCT patients as metastasis only occurs in about 2-3% of all people affected by GCT. GCT is most likely to spread to the lungs. Treatment for lung metastases can include surgery to remove the tumours or Denosumab treatment.

In the very rare case that GCT becomes cancerous and more aggressive it will be treated more like a bone sarcoma. This will involve chemotherapy and more aggressive surgery. In a few situations where a GCT is in a very difficult place in the body to control and there are no other treatment options available, then radiotherapy may be used.

What support is available?

Your feelings

There is no right or wrong way to feel or react to diagnosis of GCT. You may feel angry, sad or

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anxious about the future. You may also have concerns for how the news will affect your loved ones. You may find comfort in talking about your concerns with family members or friends.

Talking to us

Our Support Line offers practical and emotional support and advice to anyone affected by sarcoma.

- Our support line is independent and confidential
- We believe no question is a silly question
- We lend a listening ear
- We can point you in the right direction

You may also find it helpful to talk to your clinical nurse specialist or doctor about your diagnosis; they will be able to answer any questions you may have about your condition. They may also be able to put you in touch with a counsellor for additional support, providing you with a safe, confidential place to talk about your concerns. Your GP will have access to local counselling services who can provide support to people with cancer.

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Sarcoma UK is the only cancer charity in the UK focusing on all types of sarcoma.

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Sarcoma UK makes every reasonable effort to ensure that the information we provide is up-to-date, accurate and unbiased. We hope this factsheet adds to the medical advice you have received and helps you make informed decisions about your care and treatment. Please speak to a member of your care team if you are worried about any medical issues.

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