

## About Sarcoma UK

**Sarcoma UK** was set up in response to the need for reliable patient information and to act as a pressure group for change in the NHS. Its aims include:

- To provide information and support to sarcoma patients, their carers and families
- To reduce the feeling of isolation felt by patients with a rare cancer
- To support research which leads to better treatment and better outcomes for sarcoma patients

### In its first year Sarcoma UK has:

- Developed a newsletter which is published twice a year and distributed free to patients
- Created a website with advice from leading doctors and healthcare staff
- Developed an email support list which helps patients across the UK to share experiences
- Worked with CancerBACUP and Macmillan to ensure that patients seeking a supportive voice have somewhere to call
- Encouraged the major treatment centres to start local support groups
- Worked with the National Institute for Clinical Excellence to help put in place service guidelines for the treatment of sarcoma
- Worked with patients, doctors and other specialists to develop patient information leaflets
- Opened a research fund and recruited a small group of specialist doctors so that research grants can be made with appropriate advice.

This is just a start. The big challenge now is to put in place a reliable structure to meet the individual needs of patients for information and advice about their illness, and their treatment.

**Donations to support our work are welcome.**

### Further information for sarcoma patients:

Freephone telephone help services  
CancerBACUP 0808 800 1234  
Macmillan Cancer Relief 0808 808 2020

CancerBACUP also publishes information about sarcoma. Its booklets and leaflets can be obtained free of charge from 020 7696 9003

Websites with sarcoma information for patients:  
[www.sarcomauk.org](http://www.sarcomauk.org)  
[www.cancerhelp.org.uk](http://www.cancerhelp.org.uk)  
[www.cancerbacup.org.uk](http://www.cancerbacup.org.uk)

Specialist information for GIST patients  
[www.gistsupport.co.uk](http://www.gistsupport.co.uk)

General information about clinical trials  
[www.nelh.nhs.uk/clinicaltrials/](http://www.nelh.nhs.uk/clinicaltrials/)

**Sarcoma UK publishes a six monthly newsletter about sarcoma which can be found in most specialist treatment centres. If you want regular copies they are available free of charge from:**

Sarcoma UK, PO Box 128, Ludlow,  
Shropshire, SY8 1YL

Email: [info@sarcomauk.org](mailto:info@sarcomauk.org)



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want  
to  
understand  
sarcoma?

*This may help you...*

Sarcomas are cancers of connective tissue – bones, muscle, fatty tissue, cartilage, nerves etc. They are a large group of rare cancers and together account for about 1% of all cancers diagnosed – about 2400 cases a year in the UK.

Sarcomas are most common in the over 50s but they can affect all ages and around 10% of patients are children and teenagers.

This leaflet is intended to provide you with a basic understanding of the disease and of the treatments used. It also tells you where you can get more detailed information and about telephone helpline services which know about sarcoma.

## There are three main types of sarcoma

**Bone sarcomas** are primary bone tumours - in other words they have not spread to bone from somewhere else.

One of the commonest of these is osteosarcoma, which often affects children and teenagers. Ewing's sarcoma is most frequently found amongst teenagers. Altogether there are about 400 cases of bone sarcoma a year in the UK.

**Soft tissue sarcomas** are more common - about 1500 cases a year. They mostly affect adults although there are about 60 cases in children each year. They can be found almost anywhere on or in the body. There are many kinds of soft tissue sarcoma, depending on the type of tissue from which the cancer develops.

Among the more common kinds are liposarcoma (originating from fatty tissue), leiomyosarcoma (smooth or involuntary muscle), synovial sarcoma (tendons and joints) and, amongst children, rhabdomyosarcoma (voluntary muscle).

**Gastrointestinal stromal tumour** (or GIST) is a sarcoma of the stomach or intestines. It responds well to a new drug, Glivec, and its treatment is different from other sarcomas.

GIST can be a particularly aggressive cancer and many patients will have a recurrence after initial surgery. Glivec gets a response in about 80% of patients with advanced GIST. However it is a very costly treatment and the NHS has strict rules to ensure that patients are carefully monitored while taking Glivec. Glivec has no effect on other sarcomas.

Specialist information about living with GIST and Glivec is available from GIST Support UK.

[www.gistsupport.co.uk](http://www.gistsupport.co.uk)

## Treatment of Bone & Soft Tissue Sarcoma

The most common site for sarcoma is the leg and although great advances have been made in limb surgery over the last fifteen years amputation is still necessary in some cases to try and ensure that the disease does not spread.

A sarcoma will often be a painless lump. The patient may be concerned and see a doctor but because sarcomas are rare they often remain unsuspected. They are also difficult to diagnose, with the necessary specialist experience being concentrated in very few hospitals. Many patients only receive a diagnosis after numerous investigations and tests, sometimes only after surgery for a different suspected condition.

There is plenty of evidence to show that patients do best when treated at a specialist centre. These centres tend to be in the major cancer hospitals, teaching hospitals, or the leading orthopaedic hospitals.

Internal tumours may be diagnosed after surgery for other suspected problems. These tumours are often painless until they put pressure on other organs, so they can be quite large when first discovered. As soft tissue surrounds internal organs, sarcomas can be found by surgeons in a range of specialist disciplines. However, once diagnosed the patient should be followed up by a specialist sarcoma doctor.

Sarcoma treatment can be disabling or disfiguring. Although surgical techniques can now be used which avoid amputation, in some cases amputation is unavoidable. It may be the best way of curing the disease.

Most sarcoma patients will have no problems once they have recovered from initial surgery. Good surgery is the only route to a cure, though it may be supported by radiotherapy or chemotherapy, especially with bone sarcomas.

Sources of further information are listed on the back of this leaflet

## After treatment

After surgery and any other immediate treatment, your doctors will propose a follow-up routine. This is to ensure that you recover properly from surgery and also to keep an eye on you for any possible recurrence of the disease.

The follow-up is likely to include tests and x-rays. It is important to keep the follow-up appointments and to attend the clinics and tests, even though they can be quite stressful.

Local recurrence of sarcoma is not uncommon. This is where a new lump appears close to the site of the first tumour. When surgery has completely removed the initial tumour no-one can explain why this happens. Patients need to be watchful - most of these recurrences are found by patients themselves. When treated promptly, usually in a similar way to the primary tumour, the overall prognosis rarely changes.

When they spread to other parts of the body, sarcomas usually go to the lung, occasionally the liver and more rarely elsewhere. This is known as metastatic disease. Surgery may be possible and chemotherapy treatment will usually be available but the disease will no longer be curable with today's knowledge. There are instances of patients living many years having successfully responded to treatment for advanced sarcoma. If the disease becomes incurable, palliative care might include treatment to help shrink tumours.

Clinical trials are often available to support treatment, or to offer treatment when standard treatments fail. Your doctor will tell you if any trials are relevant to your situation and will be able to give full information about what the trial means for you.

Further information about clinical trials can be obtained from the telephone help services and websites listed on the back of this leaflet.