

During our first year Sarcoma UK has:

- Developed a newsletter which is being published twice a year and is distributed free to patients either direct or through specialist treatment centres
- Put in place a website with advice from leading clinicians and healthcare staff
- Developed an email support list which enables patients across the UK to share experiences
- Worked with the telephone support lines operated by Cancer Help, CancerBACUP and Macmillan to ensure that patients seeking a supportive voice have somewhere to call, night or day
- Encouraged the major treatment centres to start local support groups
- Worked with the National Institute for Clinical Excellence (the NHS regulator) to help review and put in place service guidelines for the treatment of sarcoma
- Started to work with clinicians and nursing specialists to review information and define a model for information giving which can respond to individual patient needs
- Opened a research fund and has recruited a small group of specialist clinicians 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 information structure which can meet the individual needs of patients for information and advice about their illness, and their treatment.

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

Sarcoma UK

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who are we?

Sarcoma UK

Sarcoma UK has been set up in response to the need for reliable patient information and to act as a pressure group for change in the NHS.

Its objectives are:

- 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

About sarcoma

Sarcomas are cancers of connective tissue – bones, muscle, fatty tissue, cartilage, nerves etc. They are a group of rare cancers and together account for about 1% of all cancers diagnosed – about 2000 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.

The most common site for sarcoma is the leg and although great advances have been made in limb sparing surgery over the last fifteen years amputation is still necessary in many 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 specialist experience necessary being concentrated in very few hospitals. Many patients only receive a diagnosis after many investigations and tests, sometimes only after surgery for a different suspected condition.

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. Ewings's sarcoma is also often found amongst teenagers. Altogether there are about 400 cases of bone sarcoma a year in the UK.

Soft tissue sarcomas are more frequently diagnosed - about 1400 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 sub-types of soft tissue sarcoma, depending on the tissue from which the cancer develops.

Among the more common sub-types are liposarcoma (originating from fatty tissue), leiomyosarcoma (soft muscle), synovial sarcoma (tendons and joints) and, amongst children, rhabdomyosarcoma (striated 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.

How sarcoma is treated

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

Internal tumours can be diagnosed after surgery for other suspected problems. As sarcomas affect the tissue which makes up internal organs, rather than the organ itself, they can be found by surgeons in a range of specialist disciplines. Once diagnosed the patient should be followed up by a specialist sarcoma doctor.

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

Sarcoma treatment can be disabling or disfiguring. Although surgical techniques can now be used which avoid amputation, in many sarcoma cases amputation is unavoidable. It can be the best way of avoiding the possibility of a recurrence of the disease.

If sarcoma becomes advanced, spreading to other parts of the body (also known as metastatic disease), it is more difficult to treat. Surgery may be possible and chemotherapy treatment will usually be made 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.

When they spread sarcomas usually go to the lung, occasionally the liver but rarely to other parts of the body. If disease becomes untreatable the hospital will arrange palliative care which might include further hospital treatment to help reduce tumours, and they will do what they can to help maintain a good quality of life.