Understanding sarcoma

a new patient's guide

Sarcoma UK
The bone & soft tissue cancer charity

sarcoma.org.uk

About this booklet

This booklet is aimed at anyone who has recently been diagnosed with sarcoma cancer. It explains what sarcoma is, how it is diagnosed and the treatment options available to you. It also has information on where you can go for support. It is your personal guide with space available to keep all your diagnosis information and the details of your next hospital appointments. You can also include contact details for your doctor, sarcoma clinical nurse specialist and other healthcare professionals caring for you.

You may find it useful to share the information in this booklet with your partner or family members to help them understand about sarcoma. If you have any questions about anything you read in this booklet please contact Sarcoma UK. We offer information, support and a signposting service to other organisations that can help.

The information provided in this booklet is only for adult patients. Due to the different treatment procedures for children diagnosed with sarcoma it should not be used by parents as a guide to their child's care.

Treatment may vary depending on which area of the UK you live in. Please ask your doctor or sarcoma clinical nurse specialist about the treatment options available in your area.

Contents

What is sarcoma?

Find out more about
your subtype of sarcoma at **sarcoma.org.uk / sarcoma-types**

Sarcomas are uncommon cancers that develop in the muscle, bone, nerves, cartilage, tendons, blood vessels and the fatty and fibrous tissues.

There are about 100 different types of sarcoma that fall into three main types:

- Soft tissue sarcoma
- Primary bone sarcoma
- Gastro-intestinal stromal tumours (GIST): A soft tissue sarcoma found in the stomach and intestines

> *"There are about 100 different types of sarcoma."*

Sarcomas commonly affect the arms, legs and trunk. However, they can affect almost any part of the body, on the inside or outside.Sarcomas can also develop in the stomach and intestines as well as behind the abdomen (retroperitoneal sarcomas) and the female reproductive system (gynaecological).

About 5300 new cases of sarcoma are diagnosed each year in the UK which makes up approximately 1.3% of all cancer diagnoses.

How is sarcoma diagnosed?

The earlier sarcoma is diagnosed the better the chances of successful treatment.

Sarcomas are usually found by a patient when a lump appears on the leg, arm or trunk.

They can also be found during an investigation of other symptoms or during a routine operation.

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

- Clinical examination: looking at and feeling any lump
- A scan: taking pictures of the inside of the body using ultrasound, x-ray, CT, EUS, PET or MRI
- A biopsy: taking and testing a tissue sample
- A bone scan: to investigate primary bone sarcomas

Unfortunately, some people are diagnosed with sarcoma when the cancer has spread to other parts of the body. You can find out more about this in the 'What if my cancer spreads to another part of my body?' section of this booklet on page 13.

Types of diagnostic scans

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What sort of tests will I have?

How long do I have to wait for these tests to be carried out?

When will I get my test results?

How will I get my results?

X-ray

Uses x-radiation to take images of dense tissues inside the body such as bones or tumours.

Ultrasound

A scan that uses sound waves to create images from within the body.

CT

The Computer Tomography (CT) scan takes a number of x-rays to make a 3D image of an affected area.

EUS

The Endoscopic Ultrasound Scan (EUS) uses a tube-like instrument called an endoscope with an ultrasound scanner attached. This is used to investigate GISTs.

PET

The Positron Emission Tomography (PET) scan shows up changes in tissues that use glucose as their main source of energy – for example, the brain or heart muscle. It involves an injection of a very small amount of a radioactive drug into the body. The drug travels to places where glucose is used for energy and shows up cancers because they use glucose in a different way from normal tissue.

MRI

Magnetic Resonance Imaging (MRI) uses magnets to create an image of the tissues of the body.

Bone scan

Uses radioactive chemicals called radionuclides which are injected, swallowed or breathed into the body, to take images of bones.

Endoscopy

A thin, flexible telescope called an endoscope is passed through the mouth to the stomach and small bowel. The tip of the endoscope contains a light and a tiny video camera so the doctor can see any abnormalities. The endoscope is sometimes used to take biopsies which will then be sent to a laboratory to be tested. An endoscopy can be used to investigate GISTs.

Trans-vaginal Ultrasound

An internal ultrasound scan. A probe is placed inside the vagina to get a closer look at the pelvic organs that are being examined. This scan is mostly used to investigate sarcomas in the female reproductive system.

Hysteroscopy

A procedure used to examine the inside of the uterus (womb). A narrow tube with a telescope at the end called a hysteroscope is inserted through the vagina to take images of the womb. This scan is mostly used to investigate sarcomas in the female reproductive system.

Histopathology

Examination of a tissue sample by a pathologist under a microscope to identify disease.

Blood test

Laboratory analysis of a blood sample..

> *"Your case will be managed by a team of experts."*

Understanding your diagnosis

Identifying the stage and grade of a cancer means your doctor can advise on the best course of treatment for you. It also describes the cancer in a common language which is useful when your doctor is discussing your case with other doctors or healthcare professionals.

The stage of cancer is measured by how much it has grown or spread which can be seen on the results of your tests and scans. The results from a biopsy can tell what grade the cancer is.

Grading

- **Low-grade** means the cancer cells are slow-growing, look quite similar to normal cells, are less aggressive, and are less likely to spread
- **Intermediate-grade** means the cancer cells are growing slightly faster and look more abnormal
- **High-grade** – The cancer cells are fast growing, look very abnormal, are more aggressive and are more likely to spread

Staging

- **Stage 1** means the cancer is low grade, small (less than 5cm) and has not spread to other parts of the body
- **Stage 2** means the cancer is of any grade, usually larger than stage one but has not spread to other parts of the body
- **Stage 3** means a high grade cancer that has not spread to other parts of the body
- **Stage 4** means a cancer of any grade or size that has spread to any other part of the body

Who will treat me?

The National Institute for Health and Care Excellence (NICE) recommends that anyone with sarcoma should be referred to a specialist sarcoma team for diagnosis and treatment.

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. Please see page 14 for more details.

Some people will be treated under other multidisciplinary teams (MDT) depending on the site of the tumour. For example, people with GIST may be treated by gastrointestinal (GI) specialists.

Some treatments, such as radiotherapy, may be delivered in your local hospital. Your MDT will support you throughout your treatment to ensure you get the right treatment as and when you need it.

What is the stage and grade of my cancer?

Will the stage of my cancer affect my treatment?

What treatment is available?

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Have I been referred to a specialist sarcoma centre?

If not, why not?

Who is my key worker/ sarcoma clinical nurse specialist (CNS)?

Who are the members of my MDT?

Who do I contact in an emergency or out of hours?

The type of treatment you receive will depend on the stage and grade of your cancer and the type of sarcoma you have. Your MDT will discuss your case and your doctor or nurse will talk you through your options so you are included in deciding what treatment is best for you.

Surgery

In a lot of cases, surgery is the first treatment method used for sarcoma – sometimes with additional radiotherapy or chemotherapy.
The surgeon will remove the tumour and will aim to take out an area of normal tissue around it too; this is known as taking a margin.It allows any cancer cells that are not visible to the naked eye to be removed along with the tumour which can reduce the risk of the cancer coming back.

Radiotherapy

This treatment uses high-energy radiation beams to destroy cancer cells. It is used either before or after surgery. When used before surgery it aims to reduce the size of the tumour so it can be operated on and removed. Radiotherapy is also very effective when given after surgery. This is

Sarcoma UK run a Clinical Trials Hub, where you can find more information on clinical trials that you might be able to take part in. More information can be found on the Sarcoma UK website.

particularly so for intermediate and high grade tumours and when the margins are quite close. In this case, the aim is to kill off any local cancer cells which remain in the area of the tumour. Your doctor will advise which is best for you.

Chemotherapy

This treatment uses anti-cancer drugs to destroy cancer cells. Its main use is in treating bone sarcomas, usually before or after surgery. Not all soft tissue sarcomas respond well to this type of treatment.However, it is used, on the sub-types that do respond to chemotherapy.

Clinical trials

You may be offered an opportunity to take part in a study to investigate new diagnosis methods, drugs or treatments. Some studies also look at the care and well-being of patients. Your doctor or nurse can give you more information on opportunities for you to take part in a clinical trial.

What happens when I have had my treatment?

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What are my treatment options?

What is the likely outcome of my recommended treatment?

Are there any side effects from my recommended treatment?

Can I get a second opinion? If so, how can I get one?

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

The usual practice will include:

- A chance to discuss symptoms
- An examination to look for any signs of the sarcoma returning.
- This may include an MRI or ultrasound if required after examination.
- A chest x-ray to look out for any secondary cancers in the lungs

Find out more about clinical trials at **sarcoma.org.uk/supportinformation/clinical-trials**

Will my cancer come back?

Sarcomas can reappear in the same area after the treatment of a previous tumour. This is called a recurrence.

If the cancer does reappear, it is important to get treated as quickly as possible.This could involve further surgery or radiotherapy.

Your treatment will be assessed on an individual basis. It is useful to check for recurrences yourself through self-examination. If you are worried about your sarcoma returning contact your doctor or clinical nurse specialist.

They may decide to bring forward the date of your follow up appointment to investigate your concerns

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

A recurrence of sarcoma may be accompanied by cancer in other parts of the body. When this happens, it is called metastasis or secondary cancer. Some people are diagnosed with sarcoma because their metastases have been discovered before their primary sarcoma tumour. In sarcoma patients, these secondary cancers may appear in the lungs, which is why a chest x-ray is taken at follow-up appointments.

Secondary cancers may also appear in the liver or brain. Treatment for secondary cancer may involve surgery, radiotherapy or chemotherapy as appropriate; your treatment will be assessed on an individual basis..

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Ask your doctor or sarcoma clinical nurse specialist for more information on self examination including what signs and symptoms to look out for.

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Has my cancer spread to another part of my body?
If so, where?

What support is available?

Is there a local support group in my area?

> *"Support groups around the country offer valuable support and information to patients, carers and family."*

Sarcoma UK Support Line:

Our Support Line is here for everyone who is affected by sarcoma. We believe no question is a silly question, and we lend a listening ear. Talk to us or email for information or support.

Emotional support

Sarcoma UK Support Line: Our Support Line is here for everyone who is affected by sarcoma. We believe no question is a silly question and we lend a listening ear. Talk to us or email or information or support.

Phone: 0808 801 0401
Email: supportline@sarcoma.org.uk

You can find more information about emotional support in Sarcoma UK's 'Rehabilitation and Life after Treatment' booklet, available in print or online.

Talking about it

A diagnosis of cancer can be frightening. There is no right or wrong way to feel or react to diagnosis. You may feel angry, sador anxious about the future, or have concerns for how the newswill affect your loved ones. You may find comfort in talking about your concerns with family members or friends.

Talking to others affected by sarcoma

If you don't feel comfortable discussing your concerns with family or friends, it may help to talk to other people who have been affected by sarcoma.

There are a number of sarcoma support groups supported by Sarcoma UK around the country. These offer valuable support and information to patients, carers and family members, and provide the opportunity to meet with other people in the same *situation. Most groups are run by patients and carers working together with local sarcoma clinical nurse specialists or doctors. A typical meeting may include a talk from an invited speaker on a related topic, discussion and questions,informal chat with other group members, and refreshments. There is also online support available for people affected by all types of sarcoma. Online support provides members with the opportunity to get in touch with other sarcoma patients or carers to discuss their concerns over a new diagnosis, treatment options or worries about the future.*

What counselling services are available to me?

Talking to a professional

You may find it helpful to talk to your sarcoma 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, to provide you with a safe confidential space to speak about your concerns.

> *"Your sarcoma clinical nurse specialist should be able to advise you on benefits."*

Practical support

Free prescriptions: *Patients who are being treated for cancer in England can apply for a medical exemption (MedEx) certificate which will allow you to get free prescriptions. You can get an application from your doctor and it will need to be countersigned by your GP or consultant. Prescriptions are free for all patients inScotland, Wales and Northern Ireland.*

Benefit entitlement

Your sarcoma clinical nurse specialist should be able to advise you on the types of benefits you can claim or any special funding you can apply for. Your local Citizens Advice Bureau can also give you benefits information and many branches can help you fill out application forms. Macmillan Cancer Support have a number of benefit advisors who offer financial advice and support to cancer patients including advice about returning to work following cancer treatment.

My diagnosis details

Date of diagnosis

Details of diagnosis (type of sarcoma)

Treatment plan

My sarcoma multi-disciplinary team (MDT)

You can use this space to keep the contact details of your team members who will be involved in your treatment. You may not see all the healthcare professionals listed below.

Key Worker/Clinical Nurse Specialist (CNS)
Offers support and advice, and acts as an important point of contact for patients when they have a concern.

Name

Direct telephone

Email

Notes

Pathologist
A doctor who identifies diseases by studying tissue samples

Radiologist
A doctor who specialises in diagnosing medical conditions through images, for example, x-rays.

Notes

Surgeon
Treats cancer through the removal of tumours.

Name

Direct telephone

Email

Notes

Radiographer
Takes images, such as x-rays, and may also give radiotherapy as a treatment.

Notes

Physiotherapist
Advises on exercises to help with rehabilitation before, during and after treatment with surgery, radiotherapy and chemotherapy.

Name

Direct telephone

Email

Notes

Occupational Therapist
Advises on activities of daily life and equipment to assist recovery and independent living.Also works with local social services to ensure patients are properly supported once they leave hospital.

Name

Direct telephone

Email

Notes

Other professionals

You can record the contact details of other professionals you come into contact with in the space below.

These may include a dietician, psychologist or social worker.

Name	Contact details and notes

Appointment diary

You can keep track of your hospital appointments by recording them in the space below.

Date	Hospital	Appointment/Treatment

Date	Hospital	Appointment/Treatment

This booklet has been produced by the Information and Support Team at Sarcoma UK. It has been reviewed by Sarcoma UK's Information Review Panel which includes healthcare professionals and people affected by sarcoma.

References to the source of information used to write this booklet and an acknowledgement of the members of the Information Review Panel who reviewed the booklet are available from Sarcoma UK – **info@sarcoma.org.uk**

Sarcoma UK makes every reasonable effort to ensure that the information we provide is up-to-date, accurate and unbiased. We hope this booklet 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. Sarcoma UK does not necessarily endorse the services provided by the organisations listed in our publications.

Sarcoma UK
The bone & soft tissue
cancer charity

Sarcoma UK is a national charity that funds vital research, offers support for anyone affected by sarcoma cancer and campaigns for better treatments.

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