

Understanding sarcoma:

a new patient's guide



supportline@sarcoma.org.uk
sarcoma.org.uk



The bone & soft tissue cancer charity

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?	2
How is sarcoma diagnosed?	2
Types of diagnostic scans	4
Understanding your diagnosis	5
Who will treat me?	6
What treatment is available?	7
What happens after I have had my treatment?	8
Will my cancer come back?	8
What if my cancer spreads to another part of my body?	9
What support is available?	9
My diagnosis details	12
My sarcoma multi-disciplinary team (MDT)	13

This booklet was produced by **Sarcoma UK**, the only charity in the UK focusing on all types of sarcoma. Our mission is to increase knowledge and awareness of sarcoma through ground-breaking

programmes that inspire involvement and transform the landscape for everyone affected by sarcoma. We:

- Raise sarcoma **awareness** to initiate change and improve standards of treatment and care
- Seek answers through **research**
- Provide **support & information** for the sarcoma community

Sarcoma UK

 sarcoma.org.uk

 020 7250 8271

 info@sarcoma.org.uk

We rely solely on your donations to keep producing these booklets. Any donation is welcome:

Online sarcoma.org.uk

By cheque payable to 'Sarcoma UK' and send to:
Sarcoma UK,
49-51 East Road,
London, N1 6AH

By phone 020 7250 8271

Symbols used in this booklet



Look on our website for more information:
sarcoma.org.uk



Questions you might consider asking your doctor or sarcoma clinical nurse specialist?

What is sarcoma?

Sarcomas are rare 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 or GIST – a soft tissue sarcoma found in the stomach and intestines

They can affect almost any part of the body, on the inside or the outside. Sarcomas commonly affect the arms, legs and trunk.

They also appear in the stomach and intestines as well as behind the abdomen (retroperitoneal sarcomas) and the female reproductive system (gynae sarcomas).

About 3800 new cases of sarcoma are diagnosed each year in the UK which makes up approximately 1% of all cancer diagnoses. Some types of sarcoma are more common in children and young people, such as Rhabdomyosarcoma, Ewing's sarcoma and Osteosarcoma. Other types, such as Myxofibrosarcoma and Chondrosarcoma are more common in older people.

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

“There are about 100 different types of sarcoma.”



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



What type of sarcoma do I have?

The most common types of sarcoma

Soft tissue sarcomas

- Leiomyosarcoma
- Fibroblastic sarcoma
- Liposarcoma
- Gastrointestinal stromal tumour (GIST)
- Kaposi's sarcoma (KS)
- Angiosarcoma
- Malignant peripheral nerve sheath tumour (MPNST)
- Synovial sarcoma
- Rhabdomyosarcoma

Bone sarcomas

- Chondrosarcoma
- Osteosarcoma
- Ewing's sarcoma
- Chordoma

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 9.

Types of diagnostic scans

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.



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?

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.

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

“Your case will be managed by a team of experts.”

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

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.

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. See page 13 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

? What is the stage and grade of my cancer?

Will the stage of my cancer affect my treatment?

MDT will support you throughout your treatment to ensure you get the right treatment as and when you need it.

What treatment is available?

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 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

? 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?

! Read more information on treatment options at sarcoma.org.uk



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?



Find out more about clinical trials at sarcoma.org.uk/support-information/clinical-trials



How often will I have my follow-up appointments?

Where will I have my follow-up appointments?

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 after I have had my treatment?

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

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. This 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.

What support is available?

Emotional support

Sarcoma UK Support Line

Our Support Line is here for everyone affected by sarcoma



supportline@sarcoma.org.uk

- Our Support Line is confidential
- We believe no question is a silly question



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



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

“Support groups around the country offer valuable support and information to patients, carers and family.”

- We lend a listening ear
- We can point you in the right direction

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, sad or 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 others affected by sarcoma cancer

If you do not 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.

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 providing you with a safe, confidential place to talk about your concerns.

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 form from your doctor and it will need to be countersigned by your GP or consultant. Prescriptions are free for all patients in Scotland, 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.

? Is there a local support group in my area?

! Find out more about local and online support groups at sarcoma.org.uk

? What counselling services are available to me?

“Your sarcoma clinical nurse specialist should be able to advise you on benefits.”

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.

Notes

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

Oncologist

A doctor who specialises in cancer treatments other than surgery, for example, chemotherapy or radiotherapy.

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

sarcoma.org.uk



The bone & soft tissue cancer charity



supportline@sarcoma.org.uk



sarcoma.org.uk



020 7250 8271



info@sarcoma.org.uk



@Sarcoma_UK



uk.sarcoma



49-51 East Road, London N1 6AH



The
Information
Standard

Certified member

This organisation has been certified as a producer of reliable health and social care information.

www.theinformationstandard.org

Published: April 2016 • Version 3 • Next review: April 2018