

Understanding Liposarcoma



sarcoma.org.uk



SarcomaUK
The bone & soft tissue
cancer charity

About this guide

This booklet is aimed at anyone who has been diagnosed with liposarcoma.

It explains what liposarcoma 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 of your doctor, sarcoma clinical nurse specialist or other health professionals.

You may find it useful to share the information in this booklet with your partner or family members to help them understand about liposarcoma. If you have 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.

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

The logo consists of a white rounded rectangle with a blue border. Inside the rectangle, the text "Trusted Information Creator" is written in blue. To the right of the text is a large green checkmark.

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What is liposarcoma?

Liposarcoma is a rare type of cancer that develops from fat cells. It can occur anywhere in the body, but is mostly found on the torso, limbs and in the retroperitoneum (the area in the back of the abdomen behind the peritoneum).

Liposarcoma is a form of soft-tissue sarcoma, which is a broad term for cancers that start in soft tissues.

It is mainly found in older adults and is very rare in people under the age of 30.

There are four main types of liposarcoma:

- well-differentiated liposarcoma
- dedifferentiated liposarcoma
- myxoid liposarcoma
- pleomorphic liposarcoma

Treatment for liposarcoma depends on your subtype, but typically involves surgery to remove the tumour. This is sometimes preceded or followed by radiotherapy or chemotherapy to destroy cancer cells in any of the surrounding areas.

“Liposarcoma is a rare type of cancer that develops from fat cells.”

Signs and symptoms

Symptoms of liposarcoma can vary depending on the size and location of your tumour. The main symptom of liposarcoma is a lump or swelling, often on the arm, leg or torso.

Liposarcoma that forms in the arms and legs can cause:

- A lump that grows persistently
- Swelling or numbness in the area around your lump
- Weakness of the affected arm or leg

Liposarcoma that forms in the torso (intra-abdominal or retroperitoneal) can cause:

- Stomach pain or cramping
- Gradually increasing stomach

“Symptoms of liposarcoma can vary depending on the size and location of your tumour. The main symptom of liposarcoma is a lump or swelling, often on the arm, leg or torso.”

How is liposarcoma diagnosed?

Liposarcomas are usually found by a patient when a lump appears on the arms, legs, or torso. They can also be found during an investigation of other symptoms or during a routine operation.

A diagnosis of liposarcoma may start with a visit to your GP, who will examine you and then refer you to a specialist doctor. A specialist doctor will diagnose sarcoma through a series of tests. These may include:

- **Physical 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

See page 9 for more information on different types of scans and tests.

“Liposarcomas are usually found by a patient when a lump appears on the arms, legs, or torso.”

Subtypes of liposarcoma

Well-differentiated liposarcoma

Well-differentiated liposarcoma (WDLS) is a tumour that is slow growing and painless. It generally does not spread to other parts of the body.

It is the most common subtype of liposarcoma, making up about 50% of all liposarcoma diagnoses.

It most commonly occurs in adults over the age of 50.

The tumour is often found in the limbs or the retroperitoneum. Occasionally, retroperitoneal liposarcomas may appear as a mass in the groin, meaning they can be confused with a groin hernia.

In rare cases (17% of WDLS of the retroperitoneum and 6% of WDLS of the limbs), WDLS can progress into dedifferentiated liposarcoma (see below).

Dedifferentiated liposarcoma

Dedifferentiated liposarcoma (DDLs) is a fast-growing tumour that progresses from well-differentiated liposarcoma.

It most commonly occurs in adults over the age of 50.

DDLs has a greater chance of local recurrence and metastasis than other subtypes of liposarcoma.

Recurrence occurs in 40-75% of DDLs cases and metastasis occurs in about 10-15% of cases.

Myxoid/round-cell liposarcoma

Myxoid (also known as round-cell) liposarcoma is the second most common subtype of liposarcoma, making up about 30-35% of all liposarcomas.

It mostly occurs in adults between the ages of 35-55. However, it can also occur in younger people more often than other types of liposarcoma.

The tumour is most frequently found in the limbs (in particular in the thighs).

Pleomorphic liposarcoma

Pleomorphic liposarcoma is a rare, fast-growing tumour. It tends to occur in adults between the ages of 50 and 70.

It is the least common subtype of liposarcoma, making up approximately 5-10% of all liposarcomas.

The tumour is most commonly found in the limbs, but it may also form in the stomach or chest.

This type of liposarcoma carries a high risk of recurrence and metastasis.

Scans and tests

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 put inside the body to look inside the gut to investigate GIST tumours.

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.

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.

The results from a biopsy can tell what **grade** the cancer is. 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.

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 means 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

“The results from a biopsy can tell what grade the cancer is. The stage of cancer is measured by how much it has grown or spread.”

“Your MDT will include your key worker or sarcoma clinical nurse specialist, surgeon and other healthcare professionals involved in your care.”

Who will treat me?

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

See page 22 for more details on your MDT.

What treatment is available?

“There may be a gap of several weeks between radiotherapy and surgery. This is normal and does not mean that the tumour is free to grow while waiting for surgery. The effects of radiotherapy continue to develop for several weeks after a course of treatment finishes.”

Surgery

Surgery is the main treatment used for liposarcoma – 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. In rare cases, surgical amputation may be performed.

Radiotherapy

Radiotherapy 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. Radiation therapy that is given before surgery may be more beneficial, but it can also make it more difficult for surgical wounds to heal.

Radiotherapy is also 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.

There may be a gap of several weeks between radiotherapy and surgery. This is normal and does not mean that the tumour is free to grow while

waiting for surgery. The effects of radiotherapy continue to develop for several weeks after a course of treatment finishes.

Chemotherapy

Chemotherapy uses anti-cancer drugs to destroy cancer cells. It is sometimes used in patients that have a high risk of recurrence or metastasis.

Chemotherapy is usually given in cycles. A cycle is the time between one round of chemotherapy to the next. Most cycles range from 2 to 6 weeks. A series of cycles is called a course of treatment. Each treatment of chemotherapy is followed by a rest period of a few weeks. This gives your body time to recover, and for any damaged cells to heal.

Clinical trials

You may be offered an opportunity to take part in a study to investigate new diagnosis methods or treatments. Some studies also look at the care and wellbeing of patients. Your doctor or nurse can give you more information on opportunities for you to take part in a clinical trial. You can also take a look at the Clinical Trials Hub on our website.

"You can take a look at the Clinical Trials Hub on our website."

"Surgery is the main treatment used for liposarcoma – sometimes with additional radiotherapy or chemotherapy."

What treatment will I have?

Your treatment plan will be individually tailored depending on what subtype of liposarcoma you have.

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

Well-differentiated liposarcoma

Surgery is the most common and most reliable option for treatment of WDLS.

In some cases, radiotherapy is used in addition to surgery.

The current general consensus from researchers is that chemotherapy is not effective in this subtype.

Dedifferentiated liposarcoma

Surgery is the most common and most reliable option for treatment of DDLS.

Radiotherapy is sometimes used in patients with margins of less than 10mm after surgical resection.

It's not clear yet how suitable chemotherapy is as a treatment for DDLS, but an ongoing clinical trial is investigating this.

Myxoid/round-cell liposarcoma

Surgery is the most common and most reliable option for treatment of myxoid liposarcoma.

"Your treatment plan will be individually tailored depending on what subtype of liposarcoma you have."

In extreme cases, amputation may be performed.

Myxoid also responds well to radiotherapy and chemotherapy, so they may be used in addition to surgery.

Pleomorphic liposarcoma

Surgery is the most common and reliable option for treatment of pleomorphic liposarcoma.

In extreme cases, amputation may be performed.

Some larger tumours may be treated with chemotherapy before surgery.

Radiotherapy (before or after surgery) may also be given if the surgical margin is narrow.

Side effects of treatment

You may experience side effects from your treatment. The type of side effects will depend on the type of treatment you have received. Don't be afraid to ask your clinical nurse specialist if any symptoms you are experiencing are a side effect of your treatment. Your clinical nurse specialist can also help if your symptoms are troublesome or persistent. For more information on side effects, visit our website.

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 rule out any secondary cancers occurring in the lungs

Recurrence

Sarcoma cancer can reappear in the same area after the treatment of a previous tumour; this is called a **local recurrence**.

If the cancer does reappear, it is important to get treated as quickly as possible. This could involve further surgery and/or radiotherapy; your treatment will be assessed on an individual basis. It is useful to check for recurrences yourself through self-examination: your doctor or sarcoma clinical nurse specialist can tell you what to look for.

If you are worried about your cancer returning contact your doctor or nurse; they may decide to bring forward the date of your follow up appointment to investigate your concerns.

“After treatment, you will have regular follow-up appointments for several years.”

What if my cancer spreads?

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.

Your treatment will be assessed on an individual basis.

What support is available?

Sarcoma UK Support Line

Our Support Line is here for everyone affected by sarcoma.

- Our Support Line is confidential
- We believe no question is a silly question
- We lend a listening ear
- We can point you in the right direction

0808 801 0401

supportline@sarcoma.org.uk

"Our Support Line is here for everyone affected by sarcoma - call us on 0808 801 0401 or email supportline@sarcoma.org.uk"

Emotional support

- There are a number of **Sarcoma Support Groups** across the country. These provide support and information to patients, carers, and family members, and provide an opportunity to meet locally and informally. More information can be found on our website.
- **Maggie's Centres** provide support and advice through a team of cancer support specialists, benefits advisors, nutritionists, psychologists and therapists. They have 21 centres across the UK, and can offer support online at: www.maggiescentres.org.uk
- **Macmillan Cancer Support** offer support services within hospital cancer centres and across the community. More information can be found at: www.macmillan.org.uk
- The Professional Standards Authority provide information on all accredited counselling and psychotherapy services in the UK. More information can be found at: www.professionalstandards.org.uk

“There are a number of Sarcoma Support Groups across the country.”

Practical support

Rehabilitation

There are many services which can support you throughout your treatment and recovery. More information on physical support and rehabilitation can be found in our Understanding Rehabilitation and Life After Treatment booklet.

Rehabilitation for liposarcoma can involve the services of:

- Occupational therapists
- Physiotherapists
- Dieticians
- Speech and language therapists
- Clinical nurse specialists
- Orthotics and prosthetics

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.

Grants and 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.

“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.”

What if I am struggling to get the help I need?

If you feel that you are not getting the right support or you are not getting access to the support you need, there are a number of services that can help.

- **The Patient Advice and Liaison Service (PALS)** offers confidential advice and information about healthcare related issues. PALS can help resolve concerns or provide information about the NHS complaints procedure. You can find PALS at your local NHS hospital.
- If you have any challenges getting support, the **Citizens Advice Bureau** can provide free and impartial advice. You can visit their website for information and to find the closest centre to you.
- **Advocacy services** can provide help to ensure your voice is heard. These services may give advice about ways to have more say in your care. There are many different advocacy services available, including The Advocacy People and POhWER.

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

Oncologist

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

Name

Direct telephone

Email

Notes

Surgeon

Treats cancer through the removal of tumours.

Name

Direct telephone

Email

Notes

Physiotherapist

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

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

Dietician

Advises on nutrition. They can provide advice and support on any changes you may have to make to your diet.

Name

Direct telephone

Email

Notes

Radiologist

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

Name

Direct telephone

Email

Notes

Radiographer

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

Name

Direct telephone

Email

Notes

Pathologist

A doctor who identifies diseases by studying tissue samples. 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 psychologist or social worker.

Name	Contact details and notes

Date	Hospital	Appointment / Treatment

Date	Hospital	Appointment /Treatment

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.

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.

If you would like to provide feedback on this resource, please email feedback@sarcoma.org.uk.

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SarcomaUK

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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[sarcoma.org.uk](https://www.sarcoma.org.uk)

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