Understanding Leiomyosarcoma

Sarcoma UK
The bone & soft tissue cancer charity

sarcoma.org.uk

About this guide

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

It explains what leiomyosarcoma 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.

We offer information, support, and a signposting service to other organisations that can help (details of which can be found in this booklet).

You may find it useful to share the information in this booklet with your partner or family members to help them understand about leiomyosarcoma. If you have questions about anything you read in this booklet, please contact Sarcoma UK.

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Patient Information Forum

Contents

What is leiomyosarcoma?

> *“Leiomyosarcoma is a type of sarcoma, which is a rare form of cancer.”*

Leiomyosarcoma is a type of sarcoma, which is a rare form of cancer. Leiomyosarcoma develops in the smooth muscle cells, which are sometimes called involuntary muscles because they cause organs to contract without our control.

The cancer is most commonly found in the limbs, the tummy (abdomen), the uterus, and the retroperitoneum (which is found deep in the abdomen and pelvis, behind the abdominal lining).

Leiomyosarcoma mostly affects adults and is very rare in people under 20 years of age.

Subtypes of leiomyosarcoma

> *“Leiomyosarcomas are usually found by a patient when a lump appears on the arms, legs, or trunk”*

There are two main types of leiomyosarcoma:

- Uterine leiomyosarcoma
- Soft tissue leiomyosarcoma (or non-uterine leiomyosarcoma)

Uterine leiomyosarcomas are leiomyosarcomas that originate in the uterus (also known as the womb).

Soft tissue leiomyosarcomas are leiomyosarcomas that can originate in the soft tissues of the limbs, the tummy (abdomen), and the retroperitoneum (the area in the back of the tummy).

Signs and symptoms

What are the signs and symptoms of leiomyosarcoma?

Symptoms of leiomyosarcoma can vary depending on the size and location of your tumour. You may experience all, some, or none of these symptoms before you are diagnosed with leiomyosarcoma:

A lump or swelling in the soft tissue of the body under the skin, often on the arm, leg, or trunk

- increasing in size
- is larger than 5cm
- usually painful, but not always

For uterine leiomyosarcoma, symptoms may also include:

- vaginal bleeding post-menopause
- vaginal bleeding between periods
- vaginal bleeding that feels unusual to you
- pain around the pelvis or stomach

How is leiomyosarcoma diagnosed?

What does a leiomyosarcoma diagnosis involve?

Diagnosing soft tissue leiomyosarcoma

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

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

A specialist doctor will diagnose leiomyosarcoma 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

Diagnosing uterine leiomyosarcoma

You may have a hysteroscopy, which is a procedure used to examine and diagnose problems in the uterus.

Alongside a hysteroscopy, you may also have:

- A pelvic ultrasound
- An endometrial biopsy

Uterine leiomyosarcomas can often be misdiagnosed as benign fibroids. If the fibroids continue to grow in size after menopause, you should be seen for further examination.

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

Scans and tests

Biopsy

A procedure that involves a doctor taking a small sample of tissue from a part of your body to look for any potential cancerous cells under a microscope.

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 investigate tumours.

MRI

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

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 cancerous tissue, because they use glucose in a different way from normal tissue.

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.

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

Blood test
Laboratory analysis of a blood sample.

Hysteroscopy
A hysteroscope, which is a narrow telescope with a light and camera at the end, is passed into your womb through your vagina and cervix.

> **“There are two main types of leiomyosarcoma: uterine leiomyosarcoma and soft tissue leiomyosarcoma”**

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

Who will treat me?

> *"Leiomyosarcomas are usually found by a patient when a lump appears on the arms, legs, or trunk."*

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 20 for more details on your MDT.

What treatment is available?

- Surgery
- Radiotherapy
- Chemotherapy
- Clinical trials

What treatment will I have?

Your treatment plan will be individually tailored depending on several factors, including what subtype of leiomyosarcoma you have, and where your tumour is located.

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.

Treatment may also 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.

> *"Your treatment plan will be individually tailored depending on several factors, including what subtype of leiomyosarcoma you have, and where your tumour is located."*

Surgery

Surgery is the most common treatment method for patients with leiomyosarcoma, regardless of subtype, and especially if the cancer has not spread.

For uterine leiomyosarcoma, a hysterectomy (which is a surgical procedure to remove the uterus) is often recommended if the cancer is limited to the uterus and has not spread.

Radiotherapy

Radiotherapy may also be offered if the leiomyosarcoma is located in either a limb or in the trunk.

It can be offered either before or after surgery to reduce the risk of your cancer recurring. Radiotherapy can also be offered if surgery is not possible or if the tumour cannot be completely removed.

Recent studies have shown that in leiomyosarcomas that are located in the retroperitoneum, radiotherapy may not add any benefit to surgery alone.

Studies have shown that radiotherapy is not effective in uterine leiomyosarcomas following surgery, but may be useful for inoperable tumours to help with symptoms (such as pain or bleeding).

Chemotherapy

There is limited data on the role of chemotherapy in treating soft tissue and uterine leiomyosarcoma. This means that the effectiveness of chemotherapy on leiomyosarcoma that has not spread is yet to be fully understood.

There is potentially a role for chemotherapy if the cancer has spread, if surgery is not possible or if the tumour cannot be completely removed.

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.

Summary

- **Surgery** is the most common treatment method for patients with leiomyosarcoma
- **A hysterectomy** may be offered to patients with uterine leiomyosarcoma
- **Radiotherapy** may be offered, particularly if surgery is not possible or if the tumour cannot be removed
- **Chemotherapy** may be offered, particularly if the cancer has spread, if surgery is not possible or if the tumour cannot be removed
- You may be eligible for a clinical trial - speak to your doctor or nurse or visit our website

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. At these appointments, you may have:

- 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

> *"After treatment, you will have regular follow-up appointments for several years."*

Recurrence

Leiomyosarcoma 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. Your multidisciplinary team will work closely with each other and with you to provide support and involve you in discussing all the possible treatment options.

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 experience any new symptoms or changes in your health, contact your clinical team; they may decide to bring forward the date of your follow-up appointment to investigate any concerns.

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.

> “It is useful to check for recurrences yourself through self-examination. Your doctor or sarcoma clinical nurse specialist can tell you what to look out for.”

What support is available?

> *"Our Support Line specialists are here to talk to everyone affected by sarcoma."*

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

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.maggies.org**
- **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**

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 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.

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**

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

Date	Hospital	Appointment / Treatment

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This booklet has been produced by the Information and Content 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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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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