

Understanding gynaecological sarcomas



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The bone & soft tissue cancer charity

About this booklet

This booklet is aimed at any woman who has been diagnosed with a gynaecological sarcoma. It explains what gynaecological sarcomas are, how they are 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 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 gynaecological sarcoma. 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 area of the UK you live in. Please ask your doctor or sarcoma clinical nurse specialist about the treatment options available in your area.

This booklet was produced by **Sarcoma UK**, the only charity in the UK focusing on all types of sarcoma cancer.

Our mission is to amplify awareness, inspire involvement, and fund ground-breaking research to transform the lives of everyone affected by sarcoma.



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



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Contents

What are gynaecological sarcomas?.....	2
Signs and symptoms.....	3
How are gynaecological sarcomas diagnosed?.....	4
Types of diagnostic scans.....	5
Understanding your diagnosis.....	6
Who will treat me?.....	8
What treatment is available?.....	9
Side effects of treatment.....	12
What happens after I have had my treatment?.....	12
What if my cancer spreads to another part of my body?.....	13
What support is available?.....	13
My diagnosis details.....	17
My multi-disciplinary team (MDT).....	18

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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



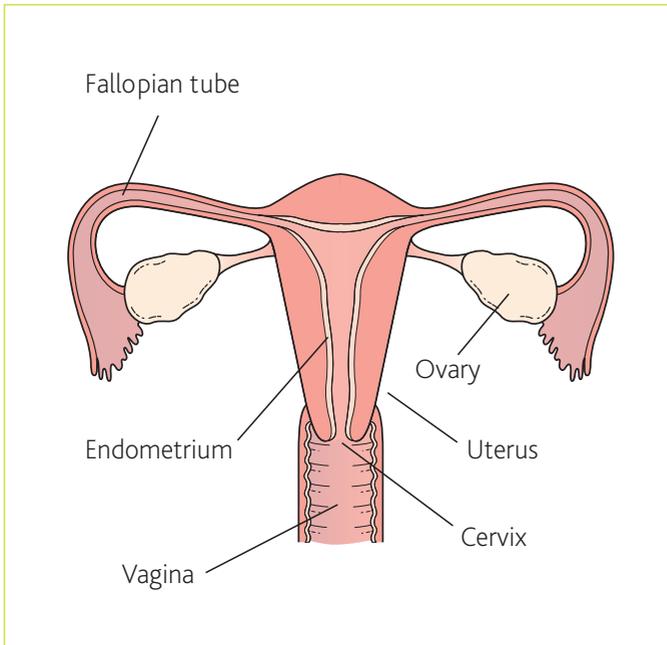
Questions you might consider asking your doctor or sarcoma clinical nurse specialist?

What are gynaecological sarcomas?

Sarcoma is cancer. It develops in the bone and soft tissue cells of the body.

“Gynaecological sarcomas can affect women of any age.”

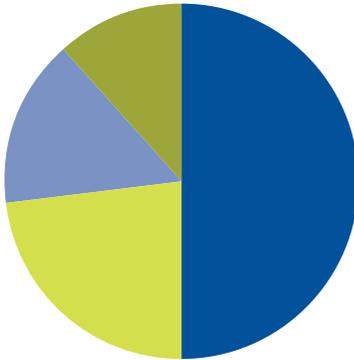
Gynaecological sarcomas, sometimes shortened to gynae sarcomas, occur in the female reproductive system: the uterus (womb), endometrium (womb lining) ovaries, vagina, vulva and fallopian tubes. They can affect women of any age although they are very rare in women under the age of 30.



Most gynaecological sarcomas (85%) occur in the uterus (womb) and 7% occur in the ovaries. The remainder occur less commonly in the vagina, vulva, fallopian tubes and other areas of the female reproductive system.

Malignant Mixed Mullerian Tumour or carcinosarcoma is a mixture of carcinoma and sarcoma, where the carcinoma component is the dominant feature. These types of cancer are not treated as a sarcoma but treated in a way that is similar to other cancers of the ovaries and uterus.

Gynaecological sarcoma types



- 52% Leiomyosarcoma
- 24% Endometrial stromal tumours
- 16% NOS
- 12% Rhabdomyosarcoma, fibrosarcoma and liposarcoma

Leiomyosarcoma – a cancer of the smooth or involuntary muscle, mostly but not always occurring in the uterus

Endometrial stromal tumours – a cancer of the connective tissue in the uterus

NOS – sarcoma not otherwise specified. This means no specific diagnosis of a sub-type of sarcoma can be made

Rhabdomyosarcoma – a cancer of the voluntary muscle, mostly occurring in the uterus and vagina

Fibrosarcoma – a cancer of the fibrous tissues, mostly occurring in the ovaries

Liposarcoma – a cancer of the fatty tissues, mostly occurring in the ovaries, vulva and uterus

What are the signs and symptoms of gynaecological sarcomas?

Symptoms of gynaecological sarcomas can vary depending on the size and location of the tumour. They may include:

- Heavy periods or bleeding in between periods
- An enlarging fibroid
- Vaginal bleeding after the menopause
- Blood in vaginal discharge
- Abdominal pain and bloating
- A noticeable lump on a section of the vulva

Symptoms can be confused with more common

“Symptoms can be confused with more common gynaecological conditions.”

gynaecological conditions for example, problems with contraceptive devices such as the coil, menopause, post menopause symptoms, and fibroids. Most women with these symptoms will be referred to a gynaecologist by their GP.

How are gynaecological sarcomas diagnosed?

A diagnosis of gynaecological sarcoma may start with a visit to your GP who will then refer you to a specialist doctor, usually a gynaecologist.

Your symptoms will be investigated further using a series of tests that may identify sarcoma. Tests may include:

- Clinical examination – looking at or feeling any lump
- A scan – taking pictures of the inside of the body using ultrasound, x-ray, CT, hysteroscopy or MRI

Some uterine sarcomas can be diagnosed from pictures taken during scans; however, many gynae sarcomas may also be found after or during a routine operation, such as surgery to remove fibroids or a hysterectomy. Some women receive their diagnosis after a pathologist has tested a sample of

tissue that has been removed during surgery.

Unfortunately, some women are diagnosed with gynaecological 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*

“Your symptoms will be investigated further using a series of tests.”

The United States Food and Drugs Administration (FDA) have expressed concern about women undergoing laparoscopic power morcellation for the treatment of uterine fibroids and the risk of inadvertent spread of unsuspected cancer (sarcoma) to the abdominal and pelvic cavities. See our website for our briefing and guidance for women who are worried about this technique.

another part of my body?' section of this booklet on page 13.

Types of scans and tests

X-ray

Uses x-radiation to produce images of the inside of the body.

Ultrasound

A scan that uses sound waves to create images from within the body. An ultrasound probe is moved over the part of the body being scanned. Gel is placed on the skin beforehand to help the scan work better.

Trans-vaginal Ultrasound

An internal ultrasound scan; a probe is placed inside the vagina to get a closer look at the area that is being examined.

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.

CT

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

PET

The Positron Emission Tomography (PET) scan involves an injection of a very small amount of a radioactive drug into

the body. The drug helps show how tissues in the body are working. It can help to diagnose and stage a cancer.

MRI

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

Histopathology

Testing a tissue sample by a pathologist under a microscope to identify disease.

Blood test

Testing a blood sample to identify infection, disease or to check your general health.

Understanding your diagnosis

A diagnosis of gynaecological sarcoma should be confirmed by a specialist sarcoma pathologist who will identify the type of sarcoma and the stage and grade of the tumour. 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 the grade of the cancer.

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

“Identifying the stage and grade of a cancer means your doctor can advise on the best course of treatment.”

- 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

The staging system used to see how far a gynaecological sarcoma has spread is called the FIGO system. It is specifically used to stage cancers of the cervix, uterus, ovary, vagina, and vulva.

- Stage 1a means the cancer is small (less than 5cm) and has not spread to other parts of the body
- Stage 1b means the cancer is larger than 5cm and has not spread to other parts of the body
- Stage 2a means the cancer is of any grade, usually larger than stage one and has spread to other parts of the female reproductive system
- Stage 2b means the cancer has spread to tissues in the pelvis other than those of the female reproductive system
- Stage 3a means a high grade cancer that has spread to tissues in the abdomen in one site
- Stage 3b means a high grade cancer that had spread to tissues in the abdomen in more than one site
- Stage 3c means the cancer has spread to the lymph nodes

“The staging system used to see how far a gynaecological sarcoma has spread is called the FIGO system.”

- Stage 4a means a cancer of any grade or size that has spread to the bladder and/or rectum (back passage)
- Stage 4b means a cancer of any grade or size that has spread to a distant part of the body from the original tumour, e.g. the lungs

Who will treat me?

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 a key worker or clinical nurse specialist, surgeon and other healthcare professionals involved in your care. Your MDT will support you throughout your treatment to ensure you get the right treatment as and when you need it. See page 17 for more details on your MDT.

The national guidelines in **England and Wales** recommend that a sarcoma MDT is involved in the treatment for women with gynaecological sarcomas.

Sometimes, the gynaecological team or gynaecological oncology team do not refer women with gynaecological sarcomas to a sarcoma MDT. Always check whether your case has been referred to a sarcoma MDT and request that this is done. Patients who are being treated under a private gynaecologist should also be referred to a sarcoma MDT. Contact Sarcoma UK for more information and advice.

Sarcoma UK
www.sarcoma.org.uk
020 7250 8271
info@sarcoma.org.uk

If your gynaecological sarcoma is diagnosed before surgery, following investigations and tests, your treatment should be managed jointly by a sarcoma MDT and a gynaecological oncology (cancer) MDT. Surgery for gynaecological sarcoma should ideally be carried out by a surgeon with specialist expertise

in gynaecological cancers, working together with sarcoma specialists to ensure you get the right treatment.

If your gynaecological sarcoma is diagnosed after surgery, you should be referred immediately to a sarcoma MDT who will review your case, manage your ongoing care, and decide on the best treatment options available to you in the future.

In **Scotland**, women with gynaecological sarcomas are treated by the gynaecological cancer specialist team.

In **Northern Ireland** women with gynaecological sarcomas are treated by the gynaecological cancer team. They will consult with the sarcoma team on any possible gynaecological sarcoma diagnoses.



What treatment is available?

The type of treatment you receive will depend on the stage and grade of your cancer, the type of gynaecological sarcoma you have, and when it is diagnosed (before or after surgery).

Surgery

In a lot of cases, the first treatment method for gynaecological sarcoma is surgery to remove the female reproductive organs called a hysterectomy. The main type of hysterectomy performed is a total abdominal hysterectomy with bilateral salpingo-oophorectomy – a hysterectomy that involves taking out the fallopian tubes (salpingectomy) and the ovaries (oophorectomy).

“In a lot of cases, the first treatment method for gynaecological sarcoma is surgery to remove the female reproductive organs.”

In younger women who are still having periods, removal of the ovaries will bring on an early menopause and lead to a loss of fertility. Please speak to your doctor prior to surgery to discuss your options for preserving your fertility. There is information on organisations that can offer you advice and support on early menopause and the loss of fertility on page 15 of this booklet.

Some pre-menopausal women with a uterine leiomyosarcoma may retain their ovaries if they wish. This operation is known as a total abdominal hysterectomy – an operation to remove the uterus and cervix but not the ovaries and fallopian tubes. You can discuss this option with your doctor.

Radiotherapy

This treatment uses high-energy radiation beams to destroy cancer cells. It can be delivered as external beam radiotherapy or occasionally delivered internally with brachytherapy. This involves putting a solid radioactive source close to, or placed into, the tumour. Radiotherapy is not commonly used after surgical treatment for uterine sarcoma but it may be used on leiomyosarcomas or endometrial stromal sarcomas that have extended outside the uterus into the pelvic region. In this case, the aim is to kill off any local cancer cells which remain in the area of the tumour.

 There is a clinical study evaluating the role of chemotherapy after surgery in high grade uterine leiomyosarcomas. Find out more at sarcoma.org.uk

Chemotherapy

This treatment uses anti-cancer drugs to destroy cancer cells. Not all gynaecological sarcomas respond well to this type of treatment and it is not commonly used to treat endometrial stromal sarcoma. It is mostly used to treat high grade leiomyosarcomas and undifferentiated endometrial sarcomas that have spread to other parts of the body. Some chemotherapy drugs used for gynaecological sarcoma (particularly leiomyosarcomas) include doxorubicin, gemcitabine, doxetaxel, trabectedin, dacarbazine and pazopanib. Less frequently, ifosfamide

is used to treat undifferentiated endometrial sarcoma.

You will be given more information about the type of treatment most suitable for you by your treatment team.

Hormone treatment

Many gynaecological sarcomas are stimulated to grow by the female growth hormones oestrogen and progesterone. These sarcomas are called hormone sensitive or hormone positive.

Around half of leiomyosarcomas in the uterus are hormone positive and endometrial stromal tumours are almost always hormone positive. Ideally, your tumour should be hormone tested after your initial surgery and the results will either be positive or negative. You can ask your oncologist to confirm whether your tumour has been hormone tested or not.

Hormone treatment is given following surgery to lower the risk of the cancer coming back or to help control advanced cancer.

Hormone therapy or anti-oestrogen therapy, uses types of drugs called aromatase inhibitors or progesterone that stops oestrogen being made in the fatty tissues and can help prevent the tumour growing.

This treatment may be used if there is oestrogen present in the tumour. Your treatment team will advise you on whether this is an appropriate treatment for you.

If you have previously been on hormone replacement therapy, please speak to your doctor to enquire as to whether this type of treatment is appropriate for you.



Women who are being treated with aromatase inhibitors may have a higher risk of osteoporosis. You may want to talk to your doctor about exploring the use of bisphosphonate therapy to protect your bone density levels whilst on this type of treatment. Women on this type of treatment should have regular bone density scans to monitor their bone density levels.



Is there a clinical trial relevant for me?



Find out more about clinical trials into the treatment of gynaecological sarcoma at sarcoma.org.uk



For more information on side effects, visit our website sarcoma.org.uk

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

Clinical trials

You may be offered an opportunity to take part in a study to investigate new diagnosis methods, drugs or treatments for gynaecological sarcomas.

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.

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.

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
- An x-ray of the pelvis to rule out any cancer in the local region
- A chest x-ray or CT scan to rule out any secondary cancers occurring in the lungs or liver

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

A gynaecological sarcoma can reappear in the same area after the treatment of a previous tumour; this is called a recurrence. 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 or liver, which is why a chest x-ray or CT scan is performed before follow-up appointments.

Secondary gynaecological sarcomas may also appear in the abdomen. Treatment for secondary cancer may involve surgery, radiotherapy or chemotherapy as appropriate; your treatment will be assessed on an individual basis. Your sarcoma MDT will review the treatments available to you and may suggest a clinical trial.

“Secondary cancers may appear in the lungs or liver.”

What support is available?

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

“You may find it helpful to talk to other women who have been affected.”

There is information on organisations that can offer you advice and support on early menopause and the loss of fertility on page 15 of this booklet.

Emotional support

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 about how the news will

affect your loved ones.

In younger women who are still having periods, removing the ovaries will bring on an early menopause and lead to a loss of fertility. This can be difficult to cope with, particularly when you are already coping with cancer. You may find comfort in talking about your concerns with family members or friends or you may find support from talking to others affected by gynaecological sarcoma.

Talking to others affected by gynaecological sarcoma

If you do not feel comfortable discussing your concerns with family or friends, you may find it useful to talk to other women who have been affected by gynaecological sarcoma.

There is an online support group for people affected by sarcoma, hosted by GroupSpaces.com. It 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. There is a private section of this group specifically for women diagnosed with a gynaecological sarcoma where you can discuss your concerns in confidence.

groupspaces.com/sarcoma is owned and run by a group of dedicated volunteers, who greet new members and monitor activity on the site. Sarcoma UK offers support



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

to members by providing useful sarcoma information.

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 women 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.

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. Your GP will have access to local counselling services who can provide support to people with cancer.

Useful contacts

There are a number of organisations that can offer specialist advice and support on the loss of fertility and other issues you may have following premature menopause.

The Daisy Network Premature Menopause Support Group

A nationwide support group for women who have experienced a premature menopause.

daisynetwork.org.uk

Fertility Friends

Information and support web community offering expert advice from registered nurses and a network of support for women affected by infertility.

fertilityfriends.co.uk

National Osteoporosis Society

Provides support and information to people affected by osteoporosis. Offers a helpline service, information booklets and facilitates support groups around the UK.

nos.org.uk

The Hysterectomy Association

Provides information to women who are facing a hysterectomy.

hysterectomy-association.org.uk

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.

My diagnosis details

Date of diagnosis

Details of diagnosis

Treatment plan

My 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 be primarily treated by a gynaecological MDT but the *UK guidelines for the management of soft tissue sarcomas* (2016) recommend that strong links to the sarcoma MDT should be maintained to ensure you receive appropriate treatment and care. 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. You may have a sarcoma CNS or a gynae-oncology CNS or both.

Name

Direct telephone

Email

Notes

Gynaecologist

A doctor who specialises in the treatment of women's diseases, especially those of the reproductive organs.

Name

Direct telephone

Email

Notes

Oncologist

A doctor who specialises in cancer treatments other than surgery, for example, chemotherapy or radiotherapy. Your oncologist may be part of a sarcoma MDT or gynae-oncology MDT.

Name

Direct telephone

Email

Notes

Surgeon

Treats cancer through the removal of tumours. Your surgeon will have expertise in gynaecology.

Name

Direct telephone

Email

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

Radiologist

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

Notes

Radiographer

A clinical technician who takes images, such as x-rays, and may also give radiotherapy as a treatment.

Notes

Pathologist

A doctor who identifies diseases by studying tissue samples.

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

<i>Name</i>	<i>Contact details and notes</i>

Appointment diary

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

<i>Date</i>	<i>Hospital</i>	<i>Appointment/Treatment</i>

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.org.uk



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