

# Understanding gynaecological sarcomas



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.**

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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](http://sarcoma.org.uk)

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

**Online** [sarcoma.org.uk](http://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](http://sarcoma.org.uk)

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

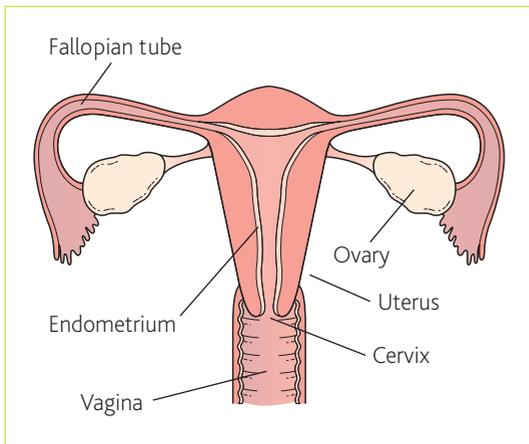
## What are gynaecological sarcomas?

Sarcomas are rare cancers that develop in the connective tissues: muscle, bones nerves, cartilage, tendons, blood vessels and the fatty and fibrous tissues.

Gynaecological sarcomas, sometimes shortened to gynae sarcomas, occur in the female reproductive system: the uterus (womb), ovaries, vagina, vulva and fallopian tubes. You may also hear the term uterine sarcoma. They can affect women of any age.

3-4% of all gynaecological cancers are sarcomas and they make up 13% of all sarcomas.

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.



The main types of gynaecological sarcomas:

- 52% are leiomyosarcoma – a cancer of the smooth or involuntary muscle, mostly but not always occurring in the uterus
- 24% are endometrial stromal tumours – a cancer of the connective tissue in the uterus

- 16% are sarcoma not otherwise specified (NOS) and include undifferentiated endometrial sarcoma (UES)

The remaining 12% are mostly made up of:

- Rhabdomyosarcoma – a cancer of the skeletal 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

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.

## 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 gynaecological conditions for example, problems with

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

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.”

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.

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.

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

## 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. A scanning microphone is moved over the part of the body that is 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 pelvic organs that are 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 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

A diagnosis of gynae 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

- 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. This is different from the staging system of most types of cancer and 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 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

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

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

- Stage 3c means the cancer has spread to the lymph nodes
- 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 your 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 at an early stage of treatment for women with gynaecological sarcomas.

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** the consultant gynaecologists consult the sarcoma oncologist to discuss any possible gynaecological sarcoma diagnosis.

## 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



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](http://www.sarcoma.org.uk)  
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“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.

with bilateral salpingo-oophorectomy – a hysterectomy that involves taking out the fallopian tubes (salpingectomy) and the ovaries (oophorectomy).

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 delivered as external beam radiotherapy or occasionally delivered internally with brachytherapy, which 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.

### 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, darcarbazine 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

Some gynaecological sarcomas react to hormones oestrogen and progesterone; these hormones feed the cancer and make the cancer grow.

50% 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 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.

 Has my tumour been hormone-tested?

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.

 There is a clinical study evaluating the role of chemotherapy after surgery in high grade uterine leiomyosarcomas. Find out more at [www.sarcoma.org.uk](http://www.sarcoma.org.uk)

**?** Is there a clinical trial relevant for me?

**!** Find out more about clinical trials into the treatment of gynaecological sarcoma at [www.sarcoma.org.uk](http://www.sarcoma.org.uk)

**!** Visit [www.sarcoma.org.uk](http://www.sarcoma.org.uk) for more information on side effects.

## 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. Please speak to your clinical nurse specialist 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

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

## 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?

### 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 for how the news will affect your loved ones.

“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.

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.

**www.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 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.

## **Practical support**

### ***Free prescriptions***

Patients who are being treated for cancer in England can apply for a medical exemption (MedEx) certificate which will allow

## **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.  
[www.daisynetwork.org.uk](http://www.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.  
[www.fertilityfriends.co.uk](http://www.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.  
[www.nos.org.uk](http://www.nos.org.uk)

### **The Hysterectomy Association**

Provides information to women who are facing a hysterectomy.  
[www.hysterectomy-association.org.uk](http://www.hysterectomy-association.org.uk)



**Find out more about local and online support groups at [www.sarcoma.org.uk/support-groups](http://www.sarcoma.org.uk/support-groups)**

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 initially treated by a gynaecological MDT but Sarcoma UK recommends that your case is also reviewed by a sarcoma MDT. 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

### Appointment diary

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

Date	Hospital	Appointment/Treatment





# Awareness • Research Support & Information



The bone & soft tissue cancer charity



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