

Gynae sarcoma

What support is available ?

Emotionally this is a very difficult stage in your illness. Taking in and understanding all the information which your doctors need to give you is not easy. It can be valuable to talk about your situation with someone independent from your family, either in person or over the telephone. Ask the nurse for information about support services at the hospital. There may also be a cancer support centre or self-support group close to your home. Macmillan keeps a list of all support groups - call Macmillan CancerLine on 0808 808 2020 (Freephone).

Help is also available from specialist gynae cancer charities. Contact numbers are on the back page.

Where should I be treated ?

You will probably have been treated in a gynae cancer unit. There are also specialist sarcoma treatment units in many large cancer centres. The National Institute of Health and Clinical Excellence (NICE) has published guidance which recommends that treatment and follow-up of uterine sarcoma patients takes place in a specialist sarcoma unit or in a gynae cancer unit with contact with a sarcoma unit, to ensure that specialist advice and clinical trials are available to patients.

Can I claim benefits ?

If you are unable to work, or your treatment has left you disabled, you may be eligible for State Benefits. A benefits advisor may be attached to the hospital to help you through the claims process.

If you need to contact a benefits adviser in your local area Macmillan can help find one for you, call 0800 500800 (Freephone). Macmillan also has a benefits advice helpline on 0808 801 0304.

How long will I live ?

It is important not to pay too much attention to statistics about survival which may be found on the Internet. Even the best doctors can only suggest a probability of survival based on studies of large numbers of patients. The prognosis for an individual cannot be determined by studies of this kind. Every individual is different.

Where to find more information

Freephone telephone help services
 Cancer Backup 0808 800 1234
 Macmillan Cancer Support 0808 808 2020

General information on sarcoma and its treatment.
www.sarcoma-uk.org
www.cancerhelp.org.uk
www.cancerbackup.org.uk

Specialist information and support for gynae cancer patients

Jo's Trust	01327 341965	www.jostrust.co.uk
Ovacome	020 7600 5141	www.ovacome.org.uk
Gynae C	01793 491116	

Treatments

www.cancerbackup.org.uk/Treatments/Chemotherapy
www.cancerbackup.org.uk/Treatments/Radiotherapy

Clinical trials explained

www.cancerbackup.org.uk/Trials/Understandingtrials
www.nelh.nhs.uk/clinicaltrials/

Information on Clinical Trials for sarcoma

www.cancerhelp.org.uk/trials/trials/default.asp

State Benefits

www.macmillan.org.uk/abetterdeal/homepage.htm
 Macmillan Benefits helpline 0808 801 0304

Sarcoma UK offers a series of short leaflets explaining the issues of living with sarcoma. These leaflets are available at the main treatment centres and at hospital information centres. We also publish a twice yearly newsletter which is available free to patients.

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Sarcoma UK is a company limited by guarantee with charitable objectives.

Registered in Cardiff 4896211

A trading company associated with The Sarcoma Trust

Reg Charity No: 1119848

You have been given this leaflet because you have been diagnosed with a uterine sarcoma.

This leaflet explains what these rare cancers are and discusses the treatment and care the doctors will be able to offer. We hope it will help you identify the questions you want to ask your doctors.

On the back page we also offer other sources of information and support which you might find valuable.

Uterine Sarcoma

Sarcoma is rare and only accounts for about 3% of all uterine cancers. There are three principle types. Carcinosarcoma or Malignant Mixed Mullerian Tumour (MMMT) accounts for about 50%. Uterine Leiomyosarcoma (ULMS) for about 35-40% and Endometrial Stromal Sarcoma (ESS) for the remainder.

Patients can find that they are being treated differently from other gynae cancer patients they meet in hospital. This should not be a matter for concern and this leaflet explains why.

Carcinosarcoma (also known as Malignant Mixed Mullerian Tumour)

Sometimes shortened to MMMT. Most cancers come from one type of tissue. A carcinoma arises from epithelial tissue - the covering or lining of the organ - while a sarcoma arises from bone, muscle, or other supporting or connective tissue. A mixed tumour has elements of both and in MMMT the cells are of both carcinoma and sarcoma types - a cancer of both the lining and connective tissue of the uterus. Hence its alternative name, carcinosarcoma.

MMMT usually affects women past the menopause. It is quite possible that the final diagnosis will not be made until after the patient has had surgery - usually a complete hysterectomy. The cause is unknown.

The principle treatment is surgery. If there is no spread of the disease surgery can be a cure but these tumours can be aggressive and it is possible that there may already be a spread of the disease at the time of diagnosis. Decisions about additional treatment will be taken after surgery. The balance between carcinoma and sarcoma cells found by the pathologist may influence the doctors on their recommendation. Radiotherapy may be offered to try and eliminate any stray cells from the area around the tumour and chemotherapy may also be offered as a follow-up (adjuvant) treatment.

Uterine Leiomyosarcoma

Leiomyosarcoma is cancer of smooth muscle. This is the muscle which we cannot consciously control. It is a very rare cancer and uterine leiomyosarcoma (ULMS) accounts for only about 100 cases a year in the UK.

Uterine LMS affects women from as young as their mid-20s although most patients will be in their 50s and 60s. It is often associated with fibroids, common benign tumours (leiomyomas) which develop in the muscular structure of the uterus. Fibroids themselves are not life-threatening but when one turns malignant it becomes a leiomyosarcoma. It is difficult to tell whether a fibroid is malignant prior to surgery, although it may be suspected, and it is usually only after a hysterectomy that the cancer is finally diagnosed.

Radiotherapy or chemotherapy are not used as often as with other uterine cancers as a follow-up to surgery, although if there is any suspicion that cancer cells remain in the body they may be recommended.

Endometrial Stromal Sarcoma

Endometrial carcinoma is one of the more common gynaecological cancers but endometrial stromal sarcoma (ESS) is one of the rarest.

The endometrium is the head of the womb. Sarcoma is cancer of connective tissue so ESS occurs in the supportive structure of the endometrium, while endometrial carcinoma occurs in the functioning tissues of the uterus. The two diseases are quite different and although an ESS patient may find herself seeing the same consultants as someone with the more common carcinoma, she will find that her treatment is different.

ESS principally affects women from 40s through to mid/late 50s. Their cause is unknown, although prior radiation for an earlier cancer is one suspected cause. As with many sarcomas, diagnosis may not be easy and it is quite likely that it will only be confirmed once tumours removed in surgery are examined in the laboratory.

Radiotherapy to the area is often given to ensure that all local tumour cells are removed. Tumours may be described as low-grade or high-grade. In the case of high-grade tumours it is

also possible that follow-up chemotherapy might be offered but there is, as yet, no evidence from research that this has a clear benefit for patients.

Hormone Sensitivity

There is evidence that both ULMS and ESS can be hormone sensitive. This may not be automatically tested but we strongly recommend to patients that they ask for their tumour to be tested for both oestrogen and progesterone receptors. If either is positive they should seek the advice of their oncologist, especially if they are taking HRT.

A new class of anti hormone drugs (known as aromatase inhibitors) may be prescribed as a potential way of stopping the tumour from returning, or of controlling tumours that have already spread.

Follow-up

The ongoing danger is of recurrence. If tumours have been removed completely there is no clear reason why some patients will be 'cured' and others have a recurrence. This is the subject of research. Recurrence may occur in the pelvic area or there may be a spread of the cancer, usually to the lungs, occasionally to the liver.

The aim of follow-up is to monitor your progress. The main danger period for recurrence is the first two years following initial surgery. Follow-up clinics will be scheduled and MRI/CT scans or chest X-rays are likely to be a feature of the routine. The patient can play a part themselves by retaining an awareness of how they are feeling and reporting any unusual pelvic discomfort, unusual coughing, breathlessness, etc at the regular clinic.

Treating recurrence

If tumours spread to other parts of the body (known as metastasis) treatment will usually be chemotherapy. A number of different drugs may be used, sometimes singly and sometimes in combinations. Treatment standards are developing all the time and clinical trials may be available, comparing existing and new treatments.