

Some more questions answered

What is a soft tissue sarcoma ?

Soft tissue sarcomas are cancers of connective tissue – muscles, nerves, fatty tissue etc. There are also bone sarcomas – primary cancers of bone. All sarcomas together account for less than 1% of all cancers. Retroperitoneal sarcomas are about 10% of that total, so they are very rare indeed.

What does retroperitoneal mean ?

The peritoneum is the tissue membrane which lines the abdomen, enclosing many of our vital organs – stomach, intestines, kidney, liver etc. Retroperitoneal means that the sarcoma lies behind that membrane, within the body.

What types of retroperitoneal soft tissue sarcomas are there?

The majority come from either fatty tissue (liposarcoma) or from a type of muscle (leiomyosarcoma). A biopsy can usually tell your surgeon which type of tumour it is but it is not always necessary for your surgeon to do a biopsy before the operation.

Will my surgeon have to remove anything else apart from the tumour?

Sometimes only the tumour needs to be removed. However, the tumour can attach itself to important organs. The scans will tell your surgeon about this. The surgeon may need to remove a kidney and/or the spleen and/or a portion of the bowel along with the tumour. But removal of one or more of these organs can still mean you make a full recovery. Before your operation, your surgeon will talk to you about whether this might be required and what this would mean for you.

Where to find more information

Freephone telephone help services

Cancerbackup 0808 800 1234

Macmillan Cancer Relief 0808 808 2020

General information on sarcoma and its treatment.

www.sarcoma-uk.org

www.cancerhelp.org.uk

More information on treatments:

www.cancerbackup.org.uk/Treatments/Surgery

www.cancerbackup.org.uk/Treatments/Chemotherapy

www.cancerbackup.org.uk/Treatments/Radiotherapy

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

Cancerbackup publishes information about sarcoma, and about treatments and trials. These booklets are available free of charge from 020 7696 9003

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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Retroperitoneal sarcoma

This leaflet has been given to you because you have been diagnosed with a soft tissue sarcoma in the retroperitoneum. This means it is inside the body cavity.

It is important to understand that at this stage in the disease it can be treated.

This leaflet explains what treatments the doctors may be able to offer and the kinds of other support which you might find valuable.

Your diagnosis ...

From the symptoms you have described to the consultant and the tests that you have gone through you have been diagnosed with a retroperitoneal sarcoma. These are very rare cancers and you will be treated at a specialist centre where the doctors have expertise in treating them.

This leaflet gives some information about retroperitoneal sarcoma and discusses the treatments which you will be offered.

Your consultant and the team they work with (known as a multi-disciplinary team) will be concerned to see that you get the treatment which meets your unique needs.

What treatments are available ?

The main treatment for these cancers is surgery. It is a complex operation and your consultant is one of a small number of surgeons in the UK who is a specialist.

The aim is to remove all the sarcoma so that no cancer cells are left in your body. The sarcoma usually grows within its own enclosure but it may attach itself to important organs, or wrap itself around them. In this case the surgeon may need to remove part of your body to ensure that the whole sarcoma is cleared.

So that the surgeon can plan the operation you will need scans and other tests to build up an accurate picture of how the sarcoma is located. Radiotherapy may be used to reduce the size of the tumour before surgery but it may not be appropriate because of where the tumour is in the body.

Your doctor will explain the aims of the treatment to you and whatever side effects the surgery may cause. You will have the opportunity to ask any questions you like and given time to discuss any issues that come up.

Your consultant may also indicate that chemotherapy following surgery may be advisable but that decision will only be finalised after the surgery.

Will surgery cure me ?

It may do so. Sarcomas are known to come back, though not every patient suffers a recurrence. If it returns it may be local, close to the site of the original tumour, or it may spread to another part of the body. This will often be to the lungs or the liver.

What does chemotherapy offer me?

Many people find the prospect of chemotherapy quite daunting. The treatment team which your consultant works with will carefully assess you following surgery to decide whether to recommend chemotherapy or not. Their aim is to try and ensure that there will not be a recurrence.

Chemotherapy today is much better managed than in the past. Your hospital will be able to give you more detailed information about the proposed treatment, how it will be given, how side effects can be managed, and the support you will have during treatment.

Chemotherapy may be given as an out-patient in a special chemotherapy unit or day ward, but some drugs have to be given as an in-patient.

A course of chemotherapy is usually a maximum of six cycles of treatment at 3-weekly intervals.

Can I refuse treatment ?

The decision whether or not to have surgery or to receive chemotherapy is very personal and you are free to choose not to have the treatment.

The doctors or nurses will explain what may happen if you do not accept it. You do not have to give a reason for not wanting to have treatment and your decision will be respected. No-one will argue against you.

If in doubt, do not rush your decision. If you decide against having treatment, tell the doctor or nurse so that they know what you have decided.

How long will I live ?

It is important not to pay 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.

Who can I talk to ?

Emotionally this is a very difficult time. 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 a self-support group, close to your home. Macmillan keeps a list of all support groups - call Macmillan CancerLine on 0808 808 2020 (Freephone).

Can my GP help ?

Your GP will be informed by the hospital of what they have told you and will be ready to help when you return home after surgery. The GP will arrange for visits from the district nurses, who can arrange support from social services if you are disabled for a period after surgery.

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.