

Soft tissue sarcomas

J A S C A P

JEET ASSOCIATION FOR SUPPORT TO CANCER PATIENTS, MUMBAI, INDIA

JASCAP

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JASCAP is a charitable trust that provides information on various aspects of cancer. This can help the patient and his family to understand the disease and its treatment and thus cope with it better.

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**** JASCAP has factsheets on each of these types of soft tissue sarcomas.**

What are soft tissue sarcomas?

Soft tissue sarcomas are rare. About 2200 people a year in the UK will be diagnosed with a sarcoma.

Soft tissue sarcomas are cancers that develop from cells in the soft, supporting tissues of the body. They can occur in muscle, fat, blood vessels or in any of the other tissues that support, surround and protect the organs of the body. Soft tissue sarcomas can also develop in specific organs, such as the womb (uterus), stomach, skin and small bowel.

Some types of sarcoma occur in children, teenagers and young adults, but generally sarcomas are more likely to develop in people over the age of 30.

Almost half of all soft tissue sarcomas occur in the limbs – especially the legs. Other common sites are the chest, abdomen and pelvis. Less commonly they may occur in the head and neck.

Bone sarcomas

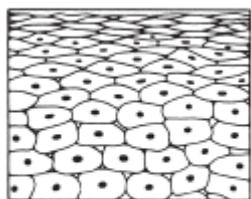
Some sarcomas, such as osteosarcomas, start in the bone. These grow and develop differently and are treated differently from soft tissue sarcomas. Occasionally it is hard to tell whether a sarcoma has started in soft tissue or bone. There are some types of sarcoma, such as Ewing's tumours, that can begin in either bone or soft tissue.

We have a separate section on cancer that starts in the bone; primary bone cancer.

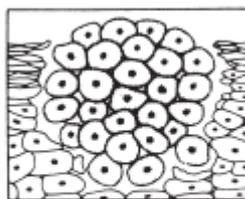
What is cancer?

The organs and tissues of the body are made up of tiny building blocks called cells. Cancer is a disease of these cells.

Cells in different parts of the body may look and work differently but most reproduce themselves in the same way. Cells are constantly becoming old and dying, and new cells are produced to replace them. Normally, cells divide in an orderly and controlled manner. If for some reason the process gets out of control, the cells carry on dividing, developing into a lump which is called a **tumour**.



Normal cells



Cells forming a tumour

Tumours can be either **benign** or **malignant**. Cancer is the name given to a malignant tumour. Doctors can tell if a tumour is benign or malignant by examining a small sample of cells under a microscope. This is called a **biopsy**.

In a benign tumour the cells do not spread to other parts of the body and so are not cancerous. However, if they continue to grow at the original site, they may cause a problem by pressing on the surrounding organs.

A malignant tumour consists of cancer cells that have the ability to spread beyond the original area. If the tumour is left untreated, it may spread into and destroy surrounding tissue. Sometimes cells break away from the original (primary) cancer. They may spread to other organs in the body through the bloodstream or lymphatic system.

The lymphatic system is part of the immune system - the body's natural defence against infection and disease. It is a complex system made up of organs, such as bone marrow, the thymus, the spleen, and lymph nodes. The lymph nodes (or glands) throughout the body are connected by a network of tiny lymphatic ducts.

When the cancer cells reach a new area they may go on dividing and form a new tumour. This is known as a **secondary cancer** or **metastasis**.

It is important to realise that cancer is not a single disease with a single type of treatment. There are more than 200 different kinds of cancer, each with its own name and treatment.

Types of cancer

Carcinomas

The majority of cancers, about 85% (85 in a 100), are carcinomas. They start in the epithelium, which is the covering (or lining) of organs and of the body (the skin). The common forms of breast, lung, prostate and bowel cancer are all carcinomas.

Carcinomas are named after the type of epithelial cell that they started in and the part of the body that is affected. There are four different types of epithelial cells:

- squamous cells - that line different parts of the body, such as the mouth, gullet (oesophagus), and the airways
- adeno cells - form the lining of all the glands in the body and can be found in organs such as the stomach, ovaries, kidneys and prostate
- transitional cells - are only found in the lining of the bladder and parts of the urinary system
- basal cells - that are found in one of the layers of the skin.

A cancer that starts in squamous cells is called a squamous cell carcinoma. A cancer that starts in glandular cells is called an adenocarcinoma. Cancers that start in transitional cells are transitional cell carcinomas, and those that start in basal cells are basal cell carcinomas.

Leukaemias and lymphomas

These occur in the tissues where white blood cells (which fight infection in the body) are formed, i.e. the bone marrow and lymphatic system. Leukaemia and lymphoma are quite rare and make up about 6.5% (6.5 in 100) of all cancers.

Sarcomas

Sarcomas are very rare. They are a group of cancers that form in the connective or supportive tissues of the body such as muscle, bone and fatty tissue. They account for less than 1% (1 in 100) of cancers.

Sarcomas are split into two main types:

- bone sarcomas - that are found in the bones
- soft tissue sarcomas - that develop in the other supportive tissues of the body.

Others forms of cancer

Brain tumours and other very rare forms of cancer make up the remainder of cancers.

Types of soft tissue sarcoma

There are many types of soft tissue sarcoma, and they tend to grow and develop differently. The most common types are described below. Your doctor will be able to give you more details about which type of sarcoma you have. Each type of sarcoma is named after the type of cell from which it has grown, rather than the part of the body in which it started.

- Fibrosarcomas
- Myxofibrosarcomas
- Desmoid tumours
- Liposarcomas
- Synovial sarcomas
- Rhabdomyosarcomas
- Leiomyosarcomas
- Malignant peripheral nerve sheath tumours (MPNST)
- Angiosarcomas
- Gastrointestinal stromal tumours (GIST)
- Kaposi's sarcoma (KS)
- Other sarcomas
- Ewing's tumours
- Soft tissue sarcomas in children

Fibrosarcomas

These sarcomas start in cells called fibrocytes, which make up the fibrous tissues that join together the inner structures of the body: for example, muscles to bones.

They are most commonly found on the arms, legs or trunk, but can occur deeper in the body. Most people first notice them as a painless, firm lump.

Myxofibrosarcomas

This is a type of fibrous sarcoma and the most common type of sarcoma in older people. They were previously called malignant fibrous histiocytomas (MFH). It is not clear which type of cell they start from. Myxofibrosarcomas can affect any part of the body, but most commonly occur in the arms or legs.

Desmoid tumours

These tumours are another type of fibrous sarcoma. They are slow-growing and are sometimes said to be halfway between a fibrosarcoma and a benign fibroma (a non-cancerous tumour of fibrous tissue). Desmoid tumours do not tend to spread to other parts of the body, but can spread into nearby tissues and so are usually treated in a similar way to sarcomas.

Liposarcomas

These sarcomas start in the body's fat cells. They can grow anywhere in the body and most commonly affect middle-aged people. Some grow very slowly (taking many years to develop) and others more quickly.

Synovial sarcomas

Synovial sarcomas usually start near to joints, such as the knee or elbow, but can occur in any part of the body. They usually appear as hard lumps and are more common in younger adults.

Rhabdomyosarcomas

Rhabdomyosarcomas grow in the active muscles of the body that we can control. These muscles are known as skeletal muscle or striated muscle. Rhabdomyosarcomas occur mostly in the head, neck and pelvis, but can occur in the arms or legs. There are three sub-types of rhabdomyosarcoma: **embryonal**, **alveolar** and **pleomorphic**.

Embryonal rhabdomyosarcomas tend to occur more commonly in children, while alveolar rhabdomyosarcomas occur more in the limbs of teenagers and young adults. Pleomorphic rhabdomyosarcoma tends to occur in middle-aged people.

Leiomyosarcomas

Leiomyosarcomas start from smooth muscle that is not under our conscious control. Smooth muscle is also called involuntary muscle and forms the walls of the womb, stomach, intestine and the blood vessels. Leiomyosarcoma is one of the more common types of sarcoma and can occur anywhere in the body.

Malignant peripheral nerve sheath tumours (MPNST)

These sarcomas arise in the cells that cover nerve cells and can occur anywhere in the body. The cells around the nerve cells are called schwann cells. MPNST can also be called malignant schwannomas or neurofibrosarcomas. They most commonly occur in people who have a rare genetic disorder called **neurofibromatosis** (von Recklinghausen's disease).

Angiosarcomas

Angiosarcomas start from the cells that make up the walls of blood or lymph vessels. If they develop from blood vessels they are called haemangiosarcomas. If they start from the lymph vessels they are called lymphangiosarcomas. Angiosarcomas sometimes arise in a part of the body that has been treated with radiotherapy many years before.

Gastrointestinal stromal tumours (GIST)

GISTs are sarcomas that develop from the connective tissues in the walls of the digestive system. The digestive system is often called the gastrointestinal (GI) tract. This type of tumour may also be called **GI stromal sarcoma**. They behave differently from other types of sarcoma and are treated very differently.

Kaposi's sarcoma (KS)

Although Kaposi's sarcoma is a type of sarcoma, it differs from other sarcomas in the way it develops. It starts from cells in the skin. Coloured patches or lumps can develop in the skin, in the mouth, and in the lymph nodes or internal organs such as the lung, liver or spleen.

Kaposi's sarcoma can affect people with a weakened immune system, including people with HIV and Aids. Other types can affect people of Jewish, Italian and West African origin. Kaposi's sarcoma is treated differently to other types of soft tissue sarcoma.

Other sarcomas

There are other, much rarer, types of sarcoma. These include:

- alveolar soft part sarcoma
- dermatofibrosarcoma protuberans (DFSP)
- desmoplastic small round cell tumours
- epithelioid sarcomas
- extraskeletal myxoid chondrosarcomas
- giant cell fibroblastoma (GCF).

Ewing's tumours

Ewing's tumours are a type of bone sarcoma, but about a third of all Ewing's tumours develop in the soft tissue and are known as **extra-osseous Ewing's tumours**. Soft tissue Ewing's sarcomas tend to behave differently to other soft tissue sarcomas and are usually treated in a similar way to bone sarcomas.

Soft tissue sarcomas in children

Soft tissue sarcomas also occur in children, particularly some types of rhabdomyosarcoma. Their symptoms and treatment may differ from those in an adult with the same sarcoma.

Our section on children's cancer discusses the treatment of children's cancers and includes information about some types of sarcoma that occur in children.

Risk factors and causes of soft tissue sarcoma

Although the cause of soft tissue sarcoma is unknown, research into this is ongoing. Sarcomas, like other cancers, are not infectious and can't be passed on to other people.

Age

Sarcomas can occur at any age but are more common in people over 30.

Genetic conditions

Most sarcomas are not caused by an inherited faulty gene that can be passed on to other family members. Members of your family are not likely to have an increased risk of developing a soft tissue sarcoma just because you have.

However, people who have some rare inherited genetic conditions are more at risk of developing a sarcoma. These conditions include neurofibromatosis, Gardner syndrome, Li-Fraumeni syndrome and retinoblastoma. You would normally know if any member of your family had one of these conditions, and their doctor would check them regularly for any sign of a sarcoma.

Previous radiotherapy treatment

Very rarely, soft tissue sarcomas may occur in a part of the body that has previously been treated with radiotherapy for another type of cancer. The sarcoma will not usually develop until at least 5–10 years after the radiotherapy treatment. Improvements in giving radiotherapy treatment mean that the risk of developing a sarcoma is very small.

Exposure to chemicals

The development of some sarcomas may be linked to exposure to some types of chemicals. The chemicals include: vinyl chloride, which is used for making plastics; some types of herbicides (weedkillers); and dioxins, which are a waste product produced during the manufacture of chemicals and fertilisers.

Injury

There is no evidence that an injury can cause a soft tissue sarcoma to develop. It's possible that an injury may draw attention to a sarcoma that was already there and not causing any symptoms, but the sarcoma will have taken many years to develop.

How common is the Soft tissue sarcoma in India?

Connective tissue and soft tissue sarcoma is one of the rare cancers diagnosed in India. It ranks lower than number 15 among all other cancers for people from the Indian subcontinent¹.

In India, between the years 2001-2003, across five urban centers - Mumbai, Delhi, Chennai, Bhopal and Bangalore, – and one rural center - Barshi, a total of 678 cases of connective tissue and soft tissue sarcoma were registered (1.54% of all cancers) for males across all age groups; while 501 cases of connective tissue and soft tissue sarcoma were registered (1.12% of all cancers) for females across all age groups. Considering all men, women and children with all types of cancers together, a grand total of 1,179 cases of connective tissue and soft tissue sarcoma (1.33% of all cancers) were registered at the six centers mentioned above, between the year 2001-2003².

The TATA Memorial Hospital (T.M.H.) in Mumbai, India registered a grand-total of 19,127 cases of all types of cancer patients in the year 2006 for men, women and children combined, out of which 372 (1.94% of the total cases) were diagnosed with the soft tissue sarcoma. Out of the total 372 patients diagnosed with soft tissue sarcoma, mentioned above at the T.M.H., 251 (68%) were males and 121 (32%) were females³.

¹ Globocan 2008: Cancer incidence and mortality rates worldwide

² Population based cancer registry 2001-2003 Mumbai, Delhi, Chennai, Bhopal, Barshi and Bangalore, Indian Cancer Society.

³ TATA Memorial Hospital Registry Data for 2006

Symptoms of soft tissue sarcomas

Sarcomas often don't cause any symptoms for a long time. They can start in any part of the body and the symptoms will depend on the part of the body that is affected.

If the sarcoma is in an arm or a leg, the most common symptom is an uncomfortable swelling in the affected limb. Occasionally, this swelling may be painful or tender, but it may also be painless.

If the sarcoma is in the central part of the body (the trunk), the symptoms will depend on which organ in the body is affected. For example:

- a sarcoma in a lung may cause a cough and breathlessness
- a sarcoma in the abdomen could cause abdominal pain, vomiting and constipation
- a sarcoma affecting the womb may cause bleeding from the vagina and pain in the lower part of the abdomen.

Generally, soft tissue sarcomas do not cause any symptoms until they are quite large and are pressing on an organ in the body or on a nerve or muscle. Things to look out for include:

- any lump, especially if it is increasing in size and is bigger than 5cm (2in)
- any lump that is painful or tender
- any lump that is deep in the body (ie not just under the skin)
- any lump that has come back after being surgically removed.

If you notice any of the above, contact your GP; but remember that these symptoms can also be caused by other conditions.

How soft tissue sarcomas are diagnosed

Usually you begin by seeing your GP, who will ask you about your symptoms and examine you. They may arrange for you to have any tests or x-rays that are necessary. You may need to be referred to hospital for these tests and for specialist advice and treatment. If your GP suspects that you might have a sarcoma you will usually be seen at the hospital within two weeks.

At the hospital, the specialist will ask about your general health and any previous medical problems. They will also examine you, which will include feeling the area where there is pain or swelling. You may be asked to have blood tests and a chest x-ray to check your general health.

You are also likely to be asked for your permission to take a sample of the lump to examine under the microscope. This is known as a **biopsy** and is the only way to tell whether the lump is a cancer or a non-cancerous (benign) tumour. You may have other tests and scans to assess the lump, before a biopsy.

A biopsy can be done in either of the following ways:

- Core needle biopsy
- Surgical biopsy

Core needle biopsy

A needle is put into the lump to take a sample of cells. Several samples may be taken. A local anaesthetic is injected first to numb the area. If the lump is near the surface of your body and can easily be felt, the doctor will probably just feel it to guide the needle in. If the lump is deep within the body (such as in the abdomen) or is harder to feel, the doctor will use an ultrasound scan or sometimes a CT scan to see where the needle is going and guide it into the right place.

When the cells are looked at under a microscope, the pathologist will be able to tell whether they are benign (not cancerous) or cancerous cells. If the lump is a sarcoma, further tests may be done on the sample to try to find out exactly what type of sarcoma it is.

Sometimes, particularly with children, the biopsy is done under a general anaesthetic.

For most people a needle biopsy will show whether the lump is a sarcoma. Sometimes, not enough cells are collected to give a clear answer, and then a surgical biopsy is needed.

Surgical biopsy

This will only be done if a needle biopsy can't be used, or doesn't give a definite result. Surgical biopsy means using a surgical knife (scalpel) to open the area and remove a tissue sample from the lump. If the lump is small enough, the whole of it may be removed.

A surgical biopsy may be done under a local or general anaesthetic, depending on the position of the lump and how deep it is within the body. If the lump turns out to be benign, you may not need to have any more treatment. If it is cancer, your doctor will discuss the treatment options with you.

In the same way as with a needle biopsy, the sample will be sent to the laboratory so that it can be tested. Often a large number of studies will be done even on a very small sample. It can take from a few days to 10 days to get all the results. This can be a worrying time for you, but it is very important that an accurate diagnosis is made so that the most appropriate treatment can be given.

It may help you to talk about your worries with a partner, close friend, relative or counsellor (see the list of useful organisations).

Further tests for soft tissue sarcomas

Your doctor may arrange for you to have one or more of the following tests to find out the size of the sarcoma, exactly where it is and whether or not it has spread to other parts of the body.

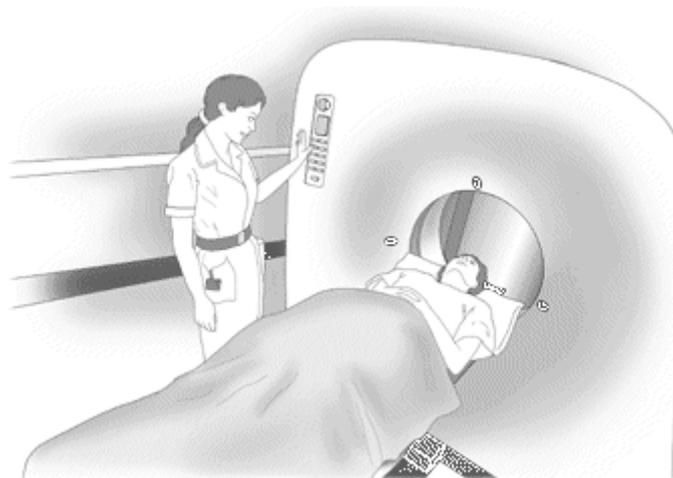
- Chest x-ray
- CT scan
- MRI scan
- Ultrasound scan of the abdomen
- PET scan
- Waiting for your test results

Chest x-ray

This will be done to check your general health and to look for any sign that the cancer has spread to your lungs, as this is one of the commonest places for soft tissue sarcomas to spread to.

CT scan

A CT (computerised tomography) scan takes a series of x-rays which builds up a three-dimensional picture of the inside of the body. The scan is painless but takes from 10 to 30 minutes. CT scans use a small amount of radiation, which will be very unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan.



Having a CT scan

You may be given a drink or injection of a dye which allows particular areas to be seen more clearly. For a few minutes, this may make you feel hot all over. If you are allergic to iodine or have asthma you could have a more serious reaction to the

injection, so it is important to let your doctor know beforehand. You will probably be able to go home shortly after the scan is over.

MRI scan

An MRI (magnetic resonance imaging) scan is similar to a CT scan, but uses magnetism instead of X-rays to build up cross-sectional pictures of your body.

During the test you will be asked to lie very still on a couch inside a long tube for about 30 minutes. This is painless but can be slightly uncomfortable, and some people feel a bit claustrophobic during the scan. It is also noisy, but you will be given earplugs or headphones. You can usually take someone with you into the room to keep you company. It is not possible for you to have an MRI scan if you have any metal in your body such as a pacemaker, or surgical clips.

Some people are given an injection of dye into a vein in the arm, but this usually does not cause any discomfort. You will probably be able to go home when the scan is over.

Ultrasound scan of the abdomen

This may be used if you have an abdominal lump. An ultrasound scan uses sound waves to look at internal organs such as the liver and the inside of the abdomen. You will usually be asked not to eat or to drink for a few hours before the test.

Once you are lying comfortably on your back, a gel is spread onto your abdomen. A small device like a microphone, which produces sound waves, is passed over the area. The sound waves are then converted into a picture by a computer. The test only takes a few minutes.

If the lump is in your womb, the ultrasound scan may be done by inserting an ultrasound device into your vagina. This is known as a transvaginal ultrasound scan and gives a very clear picture of the womb.



Having an ultrasound scan

PET scan

PET (positron emission tomography) scans are a newer type of scan and you may have to travel to a specialist centre to have one. They are not always necessary but

you can discuss with your doctor whether one would be useful in your case. PET scans can be used to find if a sarcoma has spread to other parts of the body, or to examine any lumps that remain after treatment, to see if these are scar tissue or if cancer cells are still present.

A PET scan uses low-dose radioactive glucose (a type of sugar) to measure the activity of cells in different parts of the body. A very small amount of a mildly radioactive substance is injected into a vein, usually in your arm. A scan is then taken a couple of hours later. Areas of cancer are usually more active than surrounding tissue and show up on the scan.

Waiting for your test results

It will probably take several days for the results of your tests to be ready and this waiting period will obviously be an anxious time for you. It may help if you can talk things over with a relative or close friend. You may wish to ring Cancerbackup or another support organisation for emotional support.

Staging and grading soft tissue sarcomas

The further tests already described help to find the stage and the grade of the cancer. These help the doctors to decide on the most appropriate treatment.

Grading
Staging

Grading

Grading refers to the appearance of the cancer cells under the microscope. The grade gives an idea of how quickly the cancer may develop. Grading of soft tissue sarcomas can sometimes be difficult, especially for the less common types. There are four grades, from 1 to 4.

Grade 1 means that the cancer cells look very like the normal cells of the soft tissues (called well-differentiated). They are usually slow-growing and are less likely to spread.

Grade 2 means the cancer cells have begun to look more abnormal. They are described as being moderately differentiated.

Grade 3 soft tissue sarcomas are described as being poorly differentiated – the cancer cells look very abnormal, are likely to grow quickly, and are more likely to spread.

Grade 4 soft tissue sarcomas are either poorly differentiated or undifferentiated. Undifferentiated cancer cells are primitive and immature. They don't function properly and have no specific appearance. Grade 4 soft tissue sarcomas are likely to grow more quickly and are more likely to spread.

Staging

The stage of a cancer describes its size and whether it has spread beyond its original area of the body.

Several different staging systems may be used for soft tissue sarcomas. A commonly used staging system, produced by the American Joint Committee on Cancer (AJCC), is described below and includes information about the grade of the cancer as well as the stage:

There are four major stages (from 1 to 4).

Stage 1 The cancer is low-grade (grades 1 or 2) and can either be close to the surface of the body (superficial) or deep within the body. There is no sign of any spread.

Stage 2 The cancer is high grade (grades 3 or 4). It is either superficial or deep within the body, but has not spread to lymph nodes or other parts of the body.

Stage 3 The cancer is described as high-grade, large (5cm or bigger) and deep. It has not begun to spread.

Stage 4 The cancer can be any grade, but it has spread to lymph nodes in the area or to any other part of the body, such as the lungs, head or neck. This is known as secondary cancer (or metastatic cancer).

Recurrence means that a soft tissue sarcoma has come back after it was first treated. It may come back in the area where it first started, or it may come back in another part of the body.

TNM staging system

Another staging system known as the TNM system is also commonly used. This can give your doctors more precise information about the extent of the cancer.

T describes the size of the tumour.

N describes whether the cancer has spread to the lymph nodes.

M describes whether the cancer has spread to another part of the body (secondary or metastatic cancer).

Treatment for soft tissue sarcomas

Treatment planning

Types of treatment

Second opinion

Giving your consent

Benefits and disadvantages of treatment

Treatment decisions

Treatment planning

As sarcomas are rare cancers, you should always be referred for treatment at a specialist sarcoma unit where a team of specialist doctors and others work together. This is known as a **multidisciplinary team (MDT)** and may include:

- a surgeon
- a clinical oncologist – a doctor who treats cancer with radiotherapy
- a medical oncologist – a doctor who treats cancer with chemotherapy
- a pathologist – a doctor who specialises in how disease affects the body
- a radiologist – a doctor who analyses x-rays and scans
- a specialist nurse who gives information and support to people with sarcoma.

The multidisciplinary team may also include other healthcare professionals, such as:

- a dietitian
- physiotherapist
- occupational therapist
- psychologist or counsellor.

In order to plan the best treatment for you, your doctors will take into account your age, general health, and the type, stage and grade of the sarcoma.

Types of treatment

Surgery is the most common treatment. If the soft tissue sarcoma is small and it is possible to remove it completely, surgery may be used on its own.

For larger sarcomas, and where there may be a possibility of cancer cells being left behind, **radiotherapy** is usually used as well as surgery. Radiotherapy may be given before the operation to shrink the tumour and make it easier to remove, or afterwards to try to destroy any cancer cells that may not have been removed.

Sometimes radiotherapy is used on its own or in combination with chemotherapy to treat more advanced sarcomas that can't be removed.

Chemotherapy may sometimes be given before surgery, to shrink the tumour. It is sometimes given after surgery, to try to destroy any cancer cells that have not been removed or which may have spread to other parts of the body.

For gastrointestinal stromal tumours a drug called imatinib (Glivec®) may be used before or after surgery.

It often helps to make a list of the questions you want to ask your doctor, and to take a close friend or relative with you.

Second opinion

Usually a number of cancer specialists work together as a team and they use national treatment guidelines to decide on the most suitable treatment for a patient. Even so, you may want to have another medical opinion. Either your specialist, or

your GP, will be able to refer you to another specialist for a second opinion if you feel it will be helpful. The second opinion may cause a delay to the start of your treatment, so you and your doctor need to be confident that it will give you useful information.

If you do go for a second opinion, it may be a good idea to take a friend or relative with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

Giving your consent

Before you have any treatment, your doctor will explain the aims of the treatment to you. They will usually ask you to sign a form saying that you give your permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent, and before you are asked to sign the form, you should have been given full information about:

- the type and extent of the treatment you are advised to have
- the advantages and disadvantages of the treatment
- any other types of treatments that may be appropriate
- any significant risks or side effects of the treatment.

If you do not understand what you have been told, let the staff know straight away so that they can explain again. Some cancer treatments can be very complex, so it is not unusual for people to need repeated explanations.

It is often a good idea to have a friend or relative with you when the treatment is explained, to help you remember the discussion more fully. You may also find it useful to write down a list of questions before you go to your appointment.

Patients often feel that the hospital staff are too busy to answer their questions, but it is important for you to be aware of how the treatment is likely to affect you. The staff should be willing to make time for you to ask questions.

You can always ask for more time to decide about the treatment if you feel that you can't make a decision when it is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you do not have it. It is essential to tell a doctor, or the nurse in charge, so that they can record your decision in your medical notes. You do not have to give a reason for not wanting to have treatment, but it can be helpful to let the staff know your concerns so that they can give you the best advice.

Benefits and disadvantages of treatment

Many people are frightened at the idea of having cancer treatments, because of the potential side effects that can occur. Although many of the treatments can cause side effects, these can often be well controlled with medicines. Some people ask what would happen if they did not have any treatment. Treatment can be given for different reasons and the potential benefits will vary depending upon the individual situation.

Early-stage sarcoma

In people with early-stage sarcoma, surgery is often done with the aim of curing the cancer, and additional treatments may also be given to reduce the risks of it coming back.

Advanced-stage sarcoma (metastatic)

If the cancer is at a more advanced stage, the treatment may only be able to control it – leading to an improvement in symptoms and a better quality of life. However, for some people the treatment will have no effect upon the cancer and they will get the side effects with little benefit.

Treatment decisions

If you have been offered treatment that is intended to cure your cancer, the decision whether to accept it may not be a difficult one. However, if a cure is not possible and the treatment is being given to control the cancer for a period of time, it may be more difficult to decide whether to go ahead with treatment or not.

Making decisions about treatment in these circumstances is always difficult, and you may need to discuss in detail with your doctor whether you wish to have treatment. If you choose not to, you can still be given supportive (palliative) care, with medicines to control any symptoms.

It is important that you ask your doctors and nurses any questions you have about your treatment. It is true that the hospital staff are busy, but the more you understand about your treatment, the easier it is for you and them.

Surgery for soft tissue sarcomas

Soft tissue sarcomas are very rare cancers, so once a sarcoma is diagnosed you will usually be referred to a surgeon in a large cancer hospital, who specialises in the treatment of these types of cancer. Sometimes surgery may have been done before the surgeon realised that the lump was a soft tissue sarcoma. In this situation you will then normally be referred to a sarcoma specialist. Sarcoma specialists often treat other types of cancer as well as sarcoma.

The aim of most sarcoma surgery is to remove as much of the tumour as possible. Usually, an operation called a wide local excision is done. This means removing the cancer with a border (margin) of healthy, cancer-free tissue all around it. The border of healthy tissue is removed to try to stop the cancer coming back in that area.

It is difficult to give general information about sarcoma surgery because the type of operation you have will depend on where in your body the sarcoma is. Many sarcomas are in the arm or leg, but they can grow anywhere.

Your surgeon will discuss the operation with you in detail before any choice is made about your treatment.

Surgery to the chest or abdomen
Surgery to the arms or legs
Plastic surgery

Surgery to the chest or abdomen

Surgery is usually the main treatment for soft tissue sarcomas of the trunk (the chest and abdomen). The extent of the operation will depend on the exact position of the sarcoma in the body. Your doctor will discuss this fully with you before the operation.

After your operation, you will have a tube (drip) going into a vein in your arm. This will give you fluids and nutrients for 2–3 days until you are able to eat and drink properly. The nurses on the ward will then take the drip out. Your doctor will let you know when you can start to eat again.

Radiotherapy may also be used after operations for sarcomas in the chest or abdomen to try to make sure that any remaining cancer cells are destroyed.

Surgery to the arms or legs

Major improvements have been made in surgery for soft tissue sarcomas of the arms and legs over the past few years. In the past, it was usually necessary to remove the limb (amputation) if cancer was found. A false limb (prosthesis) would then be made to replace the limb that had been removed. Amputation is still sometimes necessary, but it is now usually possible to just remove the cancer and some of the tissue around it. This is known as limb-sparing surgery and is done by using a combination of surgery, radiotherapy and chemotherapy.

Plastic surgery

Depending on the size and position of your tumour, the surgeon may have to remove a large area of tissue. This may mean that you need to have some reconstructive/cosmetic (plastic) surgery to repair the area. If this kind of surgery is needed it will be done at the same time as your operation.

The aim of plastic surgery is to make the area look and function as naturally as possible. The exact type of surgery you have will depend on where in your body the sarcoma is and how much tissue the surgeon needs to remove. If only a small area has been removed, the surgeon may be able to join the two edges together again. For larger areas a **skin graft** may be needed. This involves taking some skin from a different part of the body (known as the donor site) and using it to repair the operation site. Both sites will gradually heal over a few weeks after the operation.

Occasionally it's necessary to repair the operation site with a specialist technique using skin and tissue. This is known as a **tissue flap** and there are several different types. The surgeon will explain your operation to you and answer any questions you may have.

Limb-sparing surgery for soft tissue sarcomas

Before your operation
After your operation
Radiotherapy
Prostheses for growing children

Before your operation

Before your operation, your doctor and the nurses on the ward will discuss your treatment with you in detail to make sure that you fully understand what it involves. It is often helpful to talk to someone who has had the same operation, and the medical staff should be able to arrange this for you. On some wards a clinical nurse specialist may be available to discuss any worries that you or your carers may have.

If you have had chemotherapy, your body will need some time to recover before the surgery can be done. Usually it takes at least a couple of weeks after chemotherapy before you are ready to have your operation.

Your doctor and anaesthetist will come to see you to make sure you understand what is going to happen. They will answer any questions you may have. You will have to sign a form agreeing to the surgery. This is the time to make sure you ask all the questions you need to. Many people find that the more they know about what is going to happen, the less frightening it seems. Don't worry if you think of more questions later; just speak to your nurses again. If they can't answer your questions, they can contact the doctor to come and talk to you again.

If you have body hair on the surgery area, you will need to be shaved before your operation. This is done to reduce the risk of infection. You may be shaved in the operating theatre after you have had your anaesthetic.

After your operation

At first your limb will be firmly bandaged. This is to give the area time to heal. You will probably have a drainage tube in the wound to remove any fluid that collects in the area of the operation. It will be removed once it has stopped draining, usually after a few days.

Swelling around the wound

Sometimes fluid can build-up around the wound, especially following surgery to a buttock or limb. The swelling should gradually reduce over a few weeks. Sometimes a lot of fluid builds up around the wound; this is known as a **seroma**. It may need to be drained by a doctor or nurse.

Nutrition

You may have a drip (infusion) of fluids going into a vein in your arm. This will give you fluids and nutrients for 2–3 days until you are able to eat and drink properly. The nurses on the ward will then take the drip out.

Pain

You will have some pain and discomfort after your operation. Painkillers will be prescribed for you and these are usually very effective in keeping pain under control. To start with you will probably need a strong painkiller such as morphine. This will be given to you either as injections (given by the nurses), or through a small pump attached to a needle in your arm (which you control yourself). It is important to let the nurses know if your painkillers don't seem to be working.

If you have had surgery on your leg, a different method of pain relief (called an epidural) may be used. A fine tube is inserted through your back into the fluid between the membranes around your spinal cord; a local anaesthetic can then be continuously given into the fluid to numb the nerves that run to your legs.

Exercises

Your nurses or the physiotherapist will teach you breathing and leg exercises. You can help yourself to get better by doing the exercises as often as you are told you need to. Breathing exercises will help to stop you getting a chest infection. Leg exercises will help to stop clots forming in your legs. Chest infections or blood clots can happen if you are not moving around as much as you would normally be. Your nurses will encourage you to get up and about as soon as possible. However, limb-sparing surgery or amputation is major surgery, and you may have to stay in bed for some time afterwards; this may be from a couple of days up to a week.

Your physiotherapist will show you some exercises to keep the muscles in the limb strong and supple. This is so that as soon as it is strong enough you can use it normally. The physiotherapist will also help you to move the limb once you are able to be up and about again. Sometimes you will need a brace or support for your limb. If the operation was on your leg, you may be given crutches to use at first. This is to protect your leg while you are learning to walk again. You will probably be left with a slight limp.

Sometimes trying to walk normally with a limp puts pressure on the leg and causes pain elsewhere in the body. Although it is important to have any continuing pain checked by your doctor, it does not necessarily mean that the cancer has come back.

Going home

Most people are able to go home once their wound is well healed, usually from 7–10 days after their operation.

Radiotherapy

After limb-sparing surgery, radiotherapy treatment is usually given to the area of the operation, to destroy any cancer cells that may still be in the area. This is done because it is very difficult to be completely certain that all the cancer cells have been removed during the operation.

Prostheses for growing children

If a child has limb-sparing surgery while they are still growing it may be possible for them to have an internal prosthesis (false part of the limb) fitted that can be lengthened at a later date. The lengthening is done during a fairly minor operation, which may mean a short stay in hospital.

Amputation as a treatment for soft tissue sarcomas

It is not always possible to do limb-sparing surgery and occasionally amputation may be necessary. This may be because it's the only way to get rid of the cancer. Very occasionally, after discussion with their specialist doctor and family, people choose to have an amputation instead of limb-sparing surgery.

The preparation for amputation is similar to that for limb-sparing surgery. Psychological support for people who are about to have an amputation is very important. The nursing and medical staff looking after you will be able to offer help and support. It may also be helpful to talk to someone who has had the same operation and can give you practical advice.

After your operation
Artificial limb (prosthesis)

After your operation

You will usually have a drip for a few days to give you fluids. A bandage will be applied over the affected site to help shape the area. You'll have a tube in the wound to drain off any fluid that builds up.

You will be given painkillers to deal with any pain and discomfort. Some people have a pain that appears to come from the part of the limb that has been amputated. This is known as phantom pain or sensation. Although this pain will gradually fade, there may be some discomfort in the area for a while after the operation.

About two to three days after surgery, you will be encouraged and helped to move around. The physiotherapist will visit you shortly after your operation and show you how to do exercises to keep the muscles around the operation site strong and supple, making it easier to use an artificial limb. The physiotherapist will also show you how to do the breathing and leg exercises described above.

Artificial limb (prosthesis)

Following an amputation, most people can be fitted with an artificial limb called a prosthesis. Modern technology means that artificial limbs are now very effective, enabling people to walk, run and play sport.

A person who fits artificial limbs will visit you before or after your operation to show you the different types of prosthesis and how they work. Careful measurements have to be taken so that the prosthesis fits properly. It may take several weeks for your

prosthesis to be made and, in the meantime, you may be fitted with a temporary one so that you can begin to get used to it. The fitting of artificial limbs is usually arranged through the ward where you are being treated. Your doctor or nurse can give you more information about this.

Once your wound has healed, probably after a couple of weeks, you will be able to go home.

Radiotherapy for soft tissue sarcomas

- About radiotherapy
- Planning your treatment
- Treatment sessions
- Side effects

About radiotherapy

Radiotherapy treats cancer by using high-energy x-rays to destroy cancer cells, while doing as little harm as possible to normal cells.

Radiotherapy is an important part of the treatment for soft tissue sarcomas, particularly those affecting the arms or legs. It is usually given after surgery to destroy any remaining cancer cells. Sometimes radiotherapy may be given before an operation (**neo-adjuvant radiotherapy**), either to shrink the tumour and make it easier for the surgeon to remove it successfully, or to avoid having to amputate the limb. If the radiotherapy is given after surgery, the wound from the operation must be healed before radiotherapy treatment is started.

Radiotherapy is sometimes given on its own and may be the only treatment needed. Radiotherapy is also given to relieve symptoms and control sarcomas that can't be removed.

Radiotherapy for sarcomas is normally given as a series of short daily treatments in the hospital radiotherapy department. High-energy x-rays are directed from a machine at the area of the cancer. The treatments are usually given from Monday to Friday, with a rest at the weekend. The number of treatments will depend on the type, size and position of the cancer within your body, but the whole course of treatment for early cancer will usually last a few weeks. Each treatment takes about 10–15 minutes. Your doctor will discuss the treatment and possible side effects with you.

Planning your treatment

To make sure that the radiotherapy is as effective as possible, it has to be planned carefully. If your sarcoma is in an arm or a leg, you may have a plastic mould made. The mould helps to keep you still during radiotherapy treatment sessions and is fitted over the affected part of your body. It is made in the mould room, on your first few visits to the radiotherapy department.

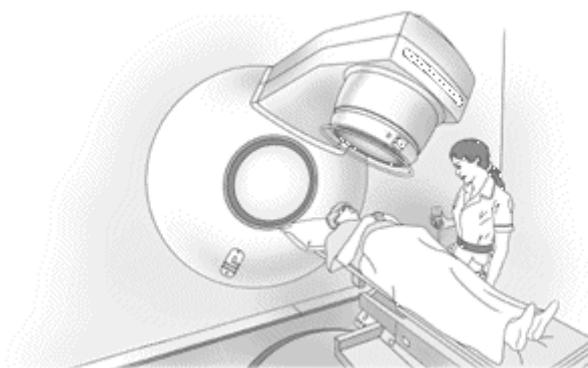
You will also be asked to lie under a large machine called a simulator, which takes x-rays or CT scans of the area to be treated. Sometimes a CT scanner can be used for the same purpose. Treatment planning is an essential element of radiotherapy and it may take a few visits. The planning sessions during your first few visits will take longer than the actual radiotherapy treatment sessions.

Marks may be drawn on your skin to help the radiographer, who gives you your treatment, to position you accurately and to show where to direct the rays. These marks must stay visible throughout your treatment but they can be washed off once the course of treatment is over. Sometimes small permanent marks (like tattoos) may be made on your skin. At the beginning of your treatment, you will be given instructions on how to look after your skin in the area being treated, as radiotherapy can make the skin sore.

Treatment sessions

Before each session of radiotherapy, the radiographer will position you carefully on the couch and make sure that you are comfortable. During your treatment, which only takes a few minutes, you will be left alone in the room, but you will be able to talk to the radiographer who will be watching you carefully.

Radiotherapy is not painful, but you do have to lie still for a few minutes while your treatment is being given. The treatment will not make you radioactive and it is perfectly safe for you to be with other people, including children, after your treatment.



Positioning the radiotherapy machine

Side effects

Radiotherapy can cause general side effects such as feeling sick and tiredness. The side effects you get will depend on the area of the body being treated and the length of your treatment. The clinical oncologist and radiographer will advise you what to expect.

Hair loss

Hair will only fall out in the area being treated by radiotherapy, so the treatment for soft tissue sarcomas will not make the hair on your head fall out. The hair that is lost may grow back after the treatment has ended, but is often lost permanently.

Skin care

During radiotherapy, the skin in the treated area may become darker or red and sore. Your radiotherapist will give you advice about skin care at the start of your treatment. Your doctor can prescribe a special cream to soothe sore skin if necessary.

Tiredness and fatigue

As radiotherapy can make you tired, try to get as much rest as you can, especially if you have to travel a long way for treatment each day.

Feeling sick

If nausea and vomiting occur they can usually be effectively treated with anti-sickness drugs (called anti-emetics), which your doctor can prescribe. If you don't feel like eating, you can replace meals with nutritious, high-calorie drinks which are available from most chemists and can be prescribed by your GP. Our section on diet has some helpful hints on how to eat well.

All these side effects should disappear gradually once the course of treatment is over, but it is important to let your doctor know if they continue.

Long-term side effects

After radiotherapy, some people may develop swelling known as lymphoedema. This happens because the lymph glands and vessels can become damaged by the radiotherapy. Lymph fluid (which circulates around the lymphatic system) is unable to pass along the vessels and builds up, causing swelling.

If lymphoedema develops it can't be cured, but it can often be treated and managed. To help prevent lymphoedema you should try to avoid getting any infection or inflammation in the area that has been treated with radiotherapy. You should try to avoid cuts or grazes in the area and help to look after your skin by using moisturisers if it gets dry.

Radiotherapy to a joint, such as the knee or elbow, may cause it to become stiff. To help prevent stiffness, it is important to keep the joint mobile by using it and doing regular exercise.

Our section on radiotherapy gives more detail about this treatment and side effects.

Chemotherapy for soft tissue sarcomas

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. As the drugs are carried in the blood, they can reach cancer cells all over the body.

Chemotherapy may sometimes be given before surgery, to shrink the tumour and make it easier to remove. This is known as **neo-adjuvant** treatment.

Chemotherapy may also sometimes be used after surgery, to try to destroy any cancer cells that were too small to be removed, or which may have spread to other parts of the body. This is known as **adjuvant** treatment.

Certain types of soft tissue sarcomas are always treated with chemotherapy. For other types it is very rarely used. Your doctor can tell you whether chemotherapy will be used to treat your type of soft tissue sarcoma.

Giving chemotherapy
Side effects

Giving chemotherapy

Chemotherapy drugs are usually given by injection into a vein (intravenously) but sometimes can be given as tablets. The most commonly used chemotherapy drugs for soft tissue sarcomas are doxorubicin and ifosfamide.

Chemotherapy is given as a session (or cycle) of treatment, which usually lasts a few days. This is followed by a rest period of a few weeks to allow your body to recover from any side effects of the treatment.

The number of cycles you have will depend on the type of sarcoma you have and how well it is responding to the drugs. If doxorubicin is given on its own you will be given it as an outpatient. You will usually be given any other types of chemotherapy as an inpatient, which means spending a few days in hospital.

Side effects

Chemotherapy can cause unpleasant side effects, but it affects everyone differently and any side effects that do occur can often be well controlled with medicines.

Lowered resistance to infection

Chemotherapy can reduce the production of white blood cells by the bone marrow, making you more likely to get an infection. This effect can begin about seven days after treatment has been given and your resistance to infection usually reaches its lowest point 10–14 days after chemotherapy. Your blood cells will then increase steadily and will usually have returned to normal before your next course of chemotherapy is due.

Contact your doctor or the hospital straight away if:

your temperature goes above 38°C (100.5°F)
you suddenly feel unwell (even with a normal temperature).

You will have a blood test before each cycle of chemotherapy, to make sure that your cells have recovered. If necessary, you may be given antibiotics to treat any infection. Occasionally it may be necessary to delay your treatment if your blood count is still low. We can send you information about how to avoid an infection if you have reduced immunity.

Bruising or bleeding

The chemotherapy can also reduce the production of platelets, which help the blood to clot. Let your doctor know if you have any unexplained bruising or bleeding, such as nosebleeds, blood spots or rashes on the skin, and bleeding gums.

Anaemia (low number of red blood cells)

While having chemotherapy, you may become anaemic. This may make you feel tired and breathless.

Feeling sick

Some of the drugs used to treat soft tissue sarcomas may make people feel sick (nauseous) and vomit. There are now very effective anti-sickness drugs (anti-emetics) to prevent or greatly reduce nausea and vomiting. Your doctor can prescribe these for you. Let your doctor know if you still feel sick, as they can prescribe other types of anti-sickness drugs for you.

Sore mouth

Some chemotherapy drugs can make your mouth sore and cause small ulcers. Regular mouthwashes are important and your nurse will show you how to do these properly.

Taste changes

You may notice that your food tastes different. Your taste will usually go back to normal after the treatment finishes. If you don't feel like eating during treatment, you could try replacing some meals with nutritious drinks or a soft diet – our section on eating well has some useful tips on coping with eating problems.

Hair loss

Unfortunately, hair loss is a common side effect of some chemotherapy drugs. You can ask your doctor whether the drugs you are taking are likely to make your hair fall out.

It may be possible to reduce the amount of hair that you lose by using scalp cooling. Cooling the scalp during chemotherapy means that fewer chemotherapy drugs reach the hair follicles, and so the hair is less likely to fall out. We can send you information about scalp cooling.

People who lose their hair often cover up by wearing wigs, hats or scarves. Your nurses can arrange for you to see a wig-fitter to help you choose a style and colour that suits you. If your hair falls out, it will grow back over a period of 3–6 months once your treatment has finished.

Tiredness

You may feel tired and have a general feeling of weakness. It is important to allow yourself plenty of time to rest.

Although they may be hard to bear at the time, these side effects will disappear over a few months once your treatment is over.

Fertility

Your ability to become pregnant or father a child may be affected by some of the chemotherapy drugs used to treat sarcomas. It is important to discuss fertility with your nurse or doctor before starting treatment as it may be possible for men to store sperm and women to store eggs or embryos for use in the future.

Some women may find that the chemotherapy treatment causes an early menopause, and they may have the signs of the menopause, such as hot flushes and sweats. In many cases, HRT (hormone replacement therapy) can be given to replace the hormones that are no longer being produced. Women with gynaecological sarcomas may not be able to have HRT because the cancer may be sensitive to hormones.

You may find it helpful to talk all this through with your doctor or one of the support organisations.

Contraception

It is not advisable to become pregnant or father a child while having any of the chemotherapy drugs used to treat sarcomas, as they may harm the developing foetus. It is important to use effective contraception during your treatment and for up to a year afterwards. You can discuss this with your doctor or specialist nurse.

Condoms should be used during sex within the first 48 hours after chemotherapy, to protect your partner from any of the drug that may be present in semen or vaginal fluid. Again, you can discuss this with your doctor.

It is important to remember that chemotherapy affects different people in different ways. Some people find they are able to lead a fairly normal life during their treatment, but many become very tired and have to take things much more slowly. Just do as much as you feel like and try not to overdo it.

Biological therapies for soft tissue sarcomas

Biological therapies are treatments based on substances that are produced naturally in the body to destroy cancer cells.

Imatinib (Glivec®)
Sunitinib (Sutent®)

Imatinib (Glivec®)

Imatinib is a type of drug known as a tyrosine kinase inhibitor. It is sometimes used to treat gastrointestinal stromal tumours (GISTs). Imatinib works by blocking (inhibiting) signals within cancer cells and preventing a series of chemical reactions that make

the cells grow and divide. The chemical it blocks is called tyrosine kinase. The effects of imatinib are very specific to GISTs. It is taken once a day as tablets.

Imatinib can cause side effects including feeling sick (nausea), vomiting, diarrhoea, a skin rash and puffiness, especially around the eyes. Some of the side effects can be reduced with other medicines.

Imatinib can sometimes control GISTs for several years.

Sunitinib (Sutent®)

Sunitinib is another tyrosine kinase inhibitor. It is sometimes used to treat GISTs that don't respond to imatinib, or if the side effects of imatinib are too much. As well as blocking signals within the cancer cells and preventing a series of chemical reactions that make the cell grow and divide, it helps to prevent the tumour developing new blood vessels. Without blood vessels the tumour can't get the nutrients it needs to survive.

Sunitinib has recently been licensed as a treatment for GISTs, but it may not be widely available. Your doctor can advise you if sunitinib is suitable for you.

Side effects of sunitinib include tiredness, diarrhoea, sore hands and feet, a sore mouth, taste changes and a loss of appetite.

Follow-up after treatment for soft tissue sarcomas

While most people recover well after surgery for soft tissue sarcomas, and are able to move around quite soon, some people take longer and need extra help. Before you go home, the medical staff will talk to you about your situation. If you live alone or have several stairs to climb, you may need some help at home.

If you have any worries about going home, make sure you discuss them with the medical staff in advance so that help can be organised. Children and teenagers often worry about falling behind at school. Home tutoring can often be arranged with the local education authority. The social worker on your ward will be able to organise this for you.

After your treatment has ended your doctor will want you to have regular check-ups and x-rays, in particular chest x-rays. These will often continue for several years. If you have any problems or notice any new symptoms in between these times (for example, a lump or swelling at the area of your operation), let your doctor know as soon as possible.

The gaps between your appointments will get longer as the years go on. This is because the risk of the cancer coming back gets steadily lower over time.

What if the cancer comes back?

Sometimes, the sarcoma may come back or spread to other parts of the body including, most often, the lungs.

If tests show that you have a small amount of cancer in your lungs, it may be possible for you to have an operation to remove the part of the lung that is affected. If this operation is necessary in your case, your doctor will discuss it fully with you.

If the cancer comes back elsewhere, your doctor will talk to you about the different treatment options available in your situation. The most common treatment for people in this situation is chemotherapy.

Living with an amputation

Developments in surgery mean that many people with soft tissue sarcomas are now able to have limb-sparing surgery instead of an amputation. Unfortunately, some people will still need to have a limb amputated to treat their cancer. Amputation is, of course, very distressing and can take a long time to come to terms with.

Feelings and emotions

Losing an arm or a leg can feel like a bereavement. You will need time to grieve for your loss and to start to cope with the emotional and practical difficulties this type of surgery can bring. Our section on the emotional effects of cancer discusses the emotions and feelings that a diagnosis of cancer can cause, and also the people and organisations available to help you to cope with them.

Body image

Even if you thought you had a good idea of what to expect before surgery, you may still feel shocked and distressed after the operation, when the full realisation of having lost an arm or leg hits you. You will be used to what your body looks like and it can be very difficult to come to terms with a major change such as an amputation.

The sense of looking different from other people can seriously affect your self-confidence and make you afraid of being rejected – both socially and sexually. At times, you may even wish you had never agreed to the operation.

It may not be easy to let other people see you after your amputation. As you and the people close to you become more used to the way you look, you will become more confident about dealing with the reactions of people you don't know so well.

Some people find it helpful to get out and about as soon as possible after the operation. However, it is important to take the time you need to get used to your amputation and to do things in your own time. You may want to take someone with you at first to give you emotional support. You may find that other people do not even notice your amputation, especially if you are wearing an artificial limb.

Help is available

You will need time and help to come to terms with your emotions, which are likely to be very strong. The staff on the ward will know this and will help you all they can. Often, there are counsellors or psychologists within the hospital, and the ward staff can arrange for you to see them.

Many people find it helpful to discuss their feelings in depth with a close friend or someone who is removed from their situation, like a counsellor. Support groups can give practical help and emotional advice, and can help stop you feeling as if you have to cope alone.

You may find it helpful to talk to someone who has had an amputation, either before or after your operation. The doctor or nurses on your ward may be able to arrange this for you.

Family and friends

Your partner, family and friends may also find it hard to come to terms with their feelings about your amputation. You may be anxious about what they will say or think, and whether you will be able to cope with their reactions.

This worry can feel very real, but most people usually find that their families and friends do not reject them, and want to do as much as possible to support them. It can help to be open about any fear of rejection.

Our section on talking about your cancer can help you find ways of talking to family and friends.

Sexuality

You may find that you feel unattractive and embarrassed about your body, and worry that no one will find you sexually attractive again. If you have a partner, you may be concerned that they will not find you attractive any more. Meeting new partners may seem particularly daunting. Our section on sexuality and cancer discusses these issues.

Research - clinical trials for soft tissue sarcomas

Cancer research trials are carried out to try to find new and better treatments for cancer. Trials that are carried out on patients are known as clinical trials.

Clinical trials may be carried out to:

- test new treatments, such as new chemotherapy drugs, gene therapy or cancer vaccines
- look at new combinations of existing treatments, or change the way they are given, to make them more effective or to reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- see which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different operation, type of chemotherapy, radiotherapy, or other treatment is better than what is already available.

Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about sarcomas and develop new treatments. You will be carefully monitored during and after the study. Usually, several hospitals around the country take part in these trials. It is important to bear in mind that some treatments that look promising at first are often later found not to be as good as existing treatments, or to have side effects that outweigh the benefits.

If you decide not to take part in a trial your decision will be respected and you do not have to give a reason. There will be no change in the way that you are treated by the hospital staff and you will be offered the best standard treatment for your situation.

Blood and tumour samples

Many blood samples and bone marrow or tumour biopsies may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you are taking part in a trial you may also be asked to give other samples which may be frozen and stored for future use, when new research techniques become available. These samples will have your name removed from them (anonymised) so you can't be identified.

The research may be carried out at the hospital where you are treated, or it may be at another hospital. This type of research takes a long time, so you are unlikely to hear the results. The samples will, however, be used to increase knowledge about the causes of cancer and its treatment. This research will, hopefully, improve the outlook for future patients.

Current research

If you have a sarcoma that has spread to another part of the body or come back (recurred) after treatment, you may be asked to take part in a trial using the chemotherapy drugs doxorubicin and ifosfamide. This is a randomised trial and half of the people will be treated with doxorubicin only. The other half will receive a combination of the two drugs.

If you have a leiomyosarcoma that can't be removed with surgery, or has spread to another part of the body, you may be asked to take part in a chemotherapy trial. The trial involves treatment with the chemotherapy drugs gemcitabine (Gemzar®) and docetaxel (Taxotere®).

A biological therapy is being tested as a treatment for people with two rare soft tissue sarcomas that affect the skin. The treatment, called imatinib (Glivec®) is a tyrosine kinase inhibitor and is being given to people with a dermato fibrosarcoma protuberans (DFSP) or a giant cell fibroblastoma (GCF).

JASCAP resources

Talking about your cancer

Practical advice and guidance for cancer patients to help them communicate with family, friends, carers and health professionals about emotional and practical issues arising from a diagnosis of cancer and cancer treatment.

Talking to children about cancer

Practical advice and guidance to help parents with cancer talk to their children about their cancer.

Talking to someone with cancer

Practical advice and guidance for friends, carers and family members to help them talk to their friend or relative with cancer, and provide emotional and practical support.

Note: JASCAP has booklets on each of the above subjects.

Questions you might like to ask your doctor or surgeon

You can fill this in before you see the doctor or surgeon, and then use it to remind yourself of the questions you want to ask, and the answers you receive.

1. _____

Answer _____

2. _____

Answer _____

3. _____

Answer _____

4. _____

Answer _____

5. _____

Answer _____

JASCAP : We need your help

We hope that you found this booklet useful.

To help other patients and their families we need and intend to extend our Patient Information Services in many ways.

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