MACMILLAN
CANCER SUPPORT

Understanding soft tissue sarcoma

> "I was diagnosed with Ewing sarcoma in the soft tissue. I had no idea that it could be cancer, everyone kept saying that it would be benign. To be honest I felt mostly shock, I didn't expect to hear it."

Ruth, diagnosed with soft tissue Ewing sarcoma

About this booklet

This booklet is about a type of cancer called soft tissue sarcoma. It is for anyone who has been diagnosed with a soft tissue sarcoma. There is also information for carers, family members and friends.

The booklet explains how soft tissue sarcoma is diagnosed and treated. It also has information about looking after yourself and getting support.

We hope it helps you deal with some of the questions or feelings you may have.

This booklet does not have information about bone sarcomas. We have another booklet about this called **Understanding primary bone cancer** (page 130).

We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 136 to 147, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (page 148).

Quotes

In this booklet, we have included quotes from people who have had a soft tissue sarcoma, which you may find helpful. These are from people who have chosen to share their story with us. This includes Ruth, who is on the cover of this booklet.

To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

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About soft tissue sarcoma

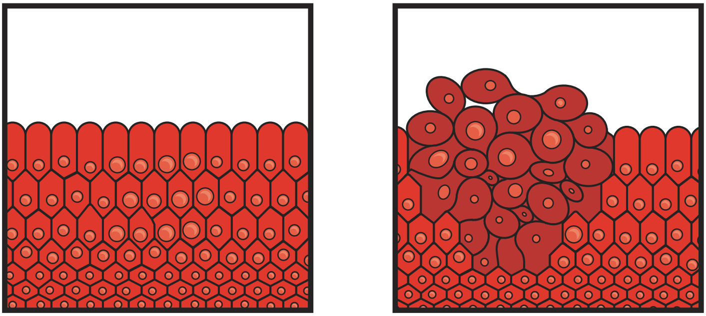
What is cancer?

Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair.

Cells receive signals from the body telling them when to divide and grow and when to stop growing. When a cell is no longer needed or cannot be repaired, it gets a signal to stop working and die.

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing, making more and more abnormal cells. These eventually form a lump (tumour).

Abnormal cells forming a tumour



Normal cells

Cells forming a tumour

Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a biopsy (pages 30 to 31). The doctors look at the sample under a microscope to look for cancer cells.

A lump that is not cancerous (benign) may grow, but cannot spread to anywhere else in the body. It usually only causes problems if it puts pressure on nearby organs.

A lump that is cancerous (malignant) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body.

The cells can travel through the blood or the lymphatic system (pages 8 to 9). When the cells reach another part of the body, they may start to grow and make another tumour. This is called a secondary cancer (metastasis).

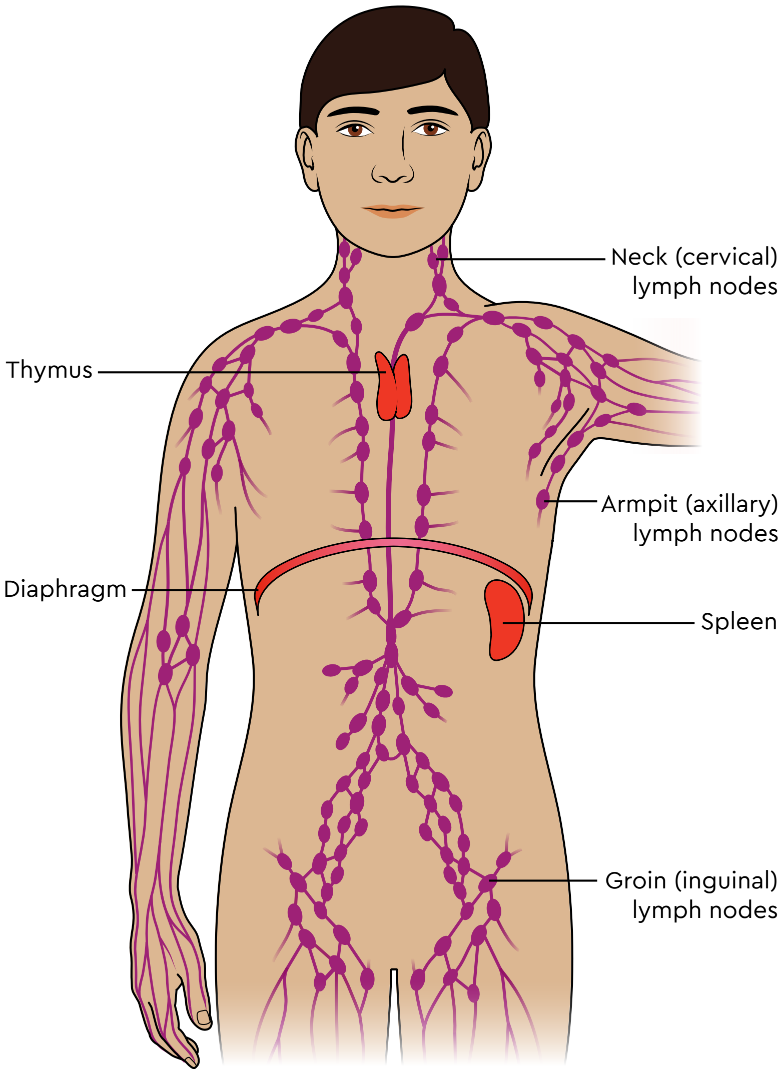
The lymphatic system

The lymphatic system helps protect us from infection and disease. It also drains lymph fluid from the tissues of the body, before returning it to the blood.

The lymphatic system is made of fine tubes called lymphatic vessels that connect to groups of lymph nodes (sometimes called lymph glands) throughout the body.

Lymph nodes are small and bean-shaped. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, lymph nodes often swell as they fight the infection.

The lymphatic system



What is soft tissue sarcoma?

Soft tissue sarcoma (STS) is a rare cancer that starts in the supporting tissues of the body. It can develop in any tissues that support, connect, surround and protect the organs. These include:

- fat
- muscle
- nerves
- fibrous tissues
- tendons and ligaments
- blood vessels.

The most common areas for soft tissue sarcoma to start are the arms and legs. But it can develop anywhere in the body, including the:

- womb (uterus)
- stomach
- small or large bowel (intestines)
- area at the back of the tummy (abdomen) called the retroperitoneum
- skin
- head and neck.

Sarcoma is more common in people over 30.

But some types of sarcoma can develop in children, teenagers and young adults, particularly some types of rhabdomyosarcoma (page 13).

The symptoms and treatment may be different from an adult with the same sarcoma. The Children's Cancer and Leukaemia Group (CCLG) has more information about children's cancers – visit **cclg.org.uk**

Bone sarcoma

Osteosarcoma is a sarcoma that starts in the bone. It grows differently from soft tissue sarcoma, and is treated differently. Sometimes it is hard to tell whether a sarcoma has started in soft tissue or bone.

Some types, such as Ewing sarcoma, can start in either the bone or the soft tissue. For more information, visit **macmillan.org.uk/ewing**

We have separate information about cancer that starts in the bone in our booklet **Understanding primary bone cancer** (page 130).

Types of soft tissue sarcoma

There are different types of soft tissue sarcoma. We describe the most common types in this section. Your doctor or specialist nurse can tell you more about which type you have.

A sarcoma is not named after the part of the body where it started. Instead, it is named after the type of cell it looks like.

Some sarcomas start from very early, undeveloped cells called stem cells. As they grow, they start to look like a particular tissue.

Fat tissue tumours

Sarcoma that starts in fat cells is called liposarcoma. It can grow anywhere in the body. The most common places are the thigh and the area in the back of the tummy, called the retroperitoneum.

Liposarcoma is more common in people aged 50 to 65.

Sometimes it grows very slowly, taking many years to develop. Or it may grow more quickly.

Muscle tissue tumours

There are 2 types of muscle tissue in the body, called smooth and skeletal muscle.

Smooth muscle sarcoma

Leiomyosarcoma (LMS) is one of the more common types of sarcoma. It develops in smooth muscle. Smooth muscle makes up the walls of internal organs, such as the womb (uterus), stomach, bowel and blood vessels. The muscle makes these organs contract (shorten) without our control.

This type of sarcoma can develop anywhere in the body. It is most common in the tummy, retroperitoneum and pelvic area. Sometimes it starts in the deep, soft tissues of the arms or legs.

Leiomyosarcoma usually develops in people aged over 50.

We have more information about leiomyosarcoma on our website. Visit **macmillan.org.uk/leiomyosarcoma**

Skeletal muscle sarcoma

Rhabdomyosarcoma (RMS) develops in skeletal muscles. These are the active muscles in our arms and legs, and other parts of the body.

Skeletal muscle sarcoma is most common in the head and neck. But it can also develop in organs such as the bladder, vagina or arms or legs. Rhabdomyosarcoma is most common in children.

We have more information about rhabdomyosarcoma on our website. Visit **macmillan.org.uk/rhabdomyosarcoma**

Peripheral nerve tumours (nerve tissue tumours)

The body's nervous system is divided into 2 parts:

- the central nervous system, which is made up of the brain and spinal cord
- the peripheral nervous system, which is made up of the nerves that carry messages between the brain, the spinal cord and the rest of the body.

Sarcoma of the peripheral nerves starts in the cells that cover the nerves. It is called a malignant peripheral nerve sheath tumour (MPNST). It can develop anywhere in the body and there are different types.

It is usually diagnosed in people aged 30 to 50 who have a rare genetic disorder called neurofibromatosis. This may also be called von Recklinghausen's disease.

Fibrous tissue tumours

Fibrous tissues join the inner structures of the body together. For example, they join muscles to bones. This tissue is made up of cells called fibrocytes. A sarcoma of the fibrous tissue is called a fibroblastic sarcoma. There are different types.

Undifferentiated pleomorphic sarcoma (UPS)

In an undifferentiated pleomorphic sarcoma or UPS, it is not clear which type of cell the sarcoma started in. UPS used to be called a malignant fibrous histiocytoma (MFH). They usually develop in the legs and arms but can affect any part of the body. UPS is more common in people aged 60 to 70.

Myxofibrosarcoma

This is a common type of soft tissue sarcoma. It usually develops in the arms, legs and central part of the body (the trunk). It is more common in older people.

Fibrosarcoma

This is a rare type of sarcoma that usually develops in the arms, legs, central part of the body (trunk) or head and neck. But it can also develop deeper in the body. It can happen at any age, but is more common in middle-aged and older people.

Dermatofibrosarcoma protuberans (DFSP)

This is a rare, slow-growing tumour. It often starts in the skin. It is usually diagnosed in people aged 20 to 30.

Fibromatosis

This is sometimes called a desmoid tumour. It is a benign tumour. Benign means the tumour is not cancer. Desmoid tumours do not usually spread to other parts of the body.

But they can spread locally into nearby tissues and may cause serious damage. Because of this, they may be treated in the same way as a cancerous sarcoma.

Blood and lymph vessel tumours

Sarcoma that starts in cells in the walls of blood or lymph vessels is called angiosarcoma. There are 2 types:

- haemangiosarcoma develops from blood vessels
- lymphangiosarcoma develops from lymph vessels.

Angiosarcoma sometimes develops in a part of the body that has been treated with radiotherapy many years before.

Other types of sarcoma

Synovial sarcoma

This tumour can develop anywhere in the body. It most commonly affects the arms and legs. It is usually diagnosed in people aged 15 to 35 but can develop at any age, including in children.

Gastrointestinal stromal tumour (GIST)

This is the most common type of soft tissue sarcoma to develop in the digestive system. The digestive system is often called the gastrointestinal (GI) tract. It is made up of the gullet, stomach and bowel.

GISTs start in nerve cells that make the muscles of the digestive system tighten and relax. They behave differently from other types of sarcoma and are treated differently.

For more information about GISTs, visit **macmillan.org.uk/gist**

Kaposi's sarcoma

Kaposi's sarcoma develops differently from other sarcomas. It starts in cells in the skin. Coloured patches or lumps can develop in the skin or mouth. Lymph nodes or internal organs such as the lungs, liver or spleen are rarely affected. It is linked with the human herpes virus (HHV8).

There are different types of Kaposi's sarcoma. Certain types can affect people with a weakened immune system. This includes people with HIV and people who have had an organ transplant. Other types of KS can happen in parts of the world where HHV8 is more common.

Kaposi's sarcoma is treated differently from other types of soft tissue sarcoma.

To learn more about Kaposi's sarcoma, visit **macmillan.org.uk/kaposis**

Soft tissue Ewing sarcoma

Ewing sarcoma is a rare cancer that usually develops in the bones. Sometimes Ewing sarcoma starts in the soft tissues of the body. This is called soft tissue Ewing sarcoma. Ewing sarcoma is most common in teenagers.

Soft tissue Ewing sarcoma behaves differently to other types of soft tissue sarcoma. It is treated in the same way as a Ewing sarcoma that starts in the bone.

We have more information about soft tissue Ewing sarcoma on our website. Visit **macmillan.org.uk/ewing**

Rarer types of sarcoma

There are other much rarer types of sarcoma that we have not explained here. These include:

- inflammatory myofibroblastic tumours (IMT)
- alveolar soft part sarcoma
- epithelioid sarcoma
- clear cell sarcoma
- desmoplastic small round cell tumours
- extraskeletal myxoid chondrosarcoma
- solitary fibrous tumours.

It can be difficult to get information about the rarer types of sarcoma. Your doctor and specialist nurse can give you more information and answer any questions you have.

You can also speak to the nurses on the Macmillan Support Line.

Call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm. ☎

Risk factors and causes

The causes of soft tissue sarcoma are not known, but researchers are trying to find out more. Certain things can affect the chances of developing a soft tissue sarcoma. These are called risk factors. Having a risk factor does not mean you will get sarcoma, and people without risk factors can still develop it.

Age

Sarcoma can develop at any age, but the risk increases as you get older.

Genetic conditions

Most types of sarcoma 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 because you have one.

But people with certain rare inherited genetic conditions are more at risk of developing a sarcoma. These include:

- neurofibromatosis – a genetic disorder that causes tumours to form on nerve tissue
- retinoblastoma – a rare eye cancer that develops in young children
- Li-Fraumeni syndrome – linked with an increased risk of developing several types of cancer, including soft tissue sarcoma
- familial adenomatous polyposis (FAP) – causes large numbers of polyps in the bowel.

If you have one of these genetic conditions, you will probably already know. Your doctor can tell you about any symptoms of sarcoma that you need to be aware of.

A family with a strong history of lots of different types of cancer, such as breast and bowel cancer, may have an increased risk of soft tissue sarcoma.

If you are worried about your family history of cancer, talk to your GP. If needed, they can refer you to a genetic clinic for testing. For more information, visit **macmillan.org.uk/genetic-counselling**

Previous radiotherapy treatment

Rarely, a soft tissue sarcoma develops in a part of the body that has been treated with radiotherapy for another type of cancer. The sarcoma does not usually develop until at least 5 to 10 years after radiotherapy.

To reduce this risk, radiotherapy is planned very carefully. The risk of developing a sarcoma afterwards is very small.

We have more information about radiotherapy on our website. Visit **macmillan.org.uk/radiotherapy**

Lymphoedema

Long-term swelling in an arm or leg is called lymphoedema. It can increase the risk of developing an angiosarcoma.

Lymphoedema can develop if the lymph nodes are removed or damaged. For example, lymphoedema may develop in:

- an arm, after surgery and radiotherapy for breast cancer
- a leg, after radiotherapy or surgery to the pelvic area.

We have more information about lymphoedema on our website. Visit **macmillan.org.uk/lymphoedema**

Exposure to chemicals

Being exposed to a chemical called vinyl chloride may increase the risk of angiosarcoma. This chemical is used for making plastic. Other chemicals such as pesticides and benzenes have been linked with sarcoma, but the evidence for this is weak.

Injury

There is no strong evidence that an injury can cause a soft tissue sarcoma to develop. It is possible that an injury may draw attention to a sarcoma that was already there, but not causing any symptoms.

We have more information about risk factors on our website. Visit **macmillan.org.uk/causes-risk-factors**

Symptoms of soft tissue sarcoma

Soft tissue sarcoma can start in any part of the body. The symptoms depend on the part of the body affected. Often, they do not cause any symptoms until they start pressing on an organ, nerve or muscle.

The main symptom is a lump or swelling that is:

- getting bigger
- bigger than 5cm (2in) – about the size of a golf ball
- painful or tender.

Most soft tissue lumps are not cancer. But if you notice any of these symptoms, get them checked by your GP. They can arrange a scan.

Symptoms of sarcoma in an arm or leg

The most common symptom of sarcoma in an arm or leg is a lump that gets bigger.

Sometimes the swelling is painful or tender, but it may be painless.

Symptoms of sarcoma in the central part of the body

If there is a sarcoma in the central part of the body (the trunk), symptoms will depend on the organ that is affected. The following are examples of sarcomas that start in the trunk:

- Sarcoma in a lung can cause a cough and breathlessness.
- Sarcoma in the tummy (abdomen) can cause pain and swelling in the tummy, vomiting (being sick) and constipation.
- A gastrointestinal stromal tumour (GIST) can cause bleeding in the bowel, dark-coloured poo and blood in vomit. It may also cause symptoms of anaemia, such as shortness of breath and tiredness. Visit **macmillan.org.uk/GIST** for more information.
- Sarcoma in the womb can cause bleeding from the vagina or pain in the pelvis (lower tummy). To learn more, visit **macmillan.org.uk/leiomyosarcoma**

Symptoms of sarcoma in the skin

The main symptom of sarcoma in the skin is usually a small patch of skin that is firm, slightly raised and purplish or reddish.

Diagnosing soft tissue sarcoma

How soft tissue sarcoma is diagnosed

You usually start by seeing your GP, who will examine you. They may arrange for you to have tests. This may include an ultrasound of the lump. If they are not sure what the problem is or think your symptoms could be caused by cancer, they will refer you to a specialist doctor.

If your GP thinks you might have a sarcoma, you should be seen at the hospital within 2 weeks. Your doctor can refer you to see a specialist within 2 days if you are 24 years old or under and have either:

- a lump that is getting bigger
- an uncertain or suspicious ultrasound result.

At the hospital

The specialist doctor will ask about your symptoms and your general health. They also examine you and the area where there is swelling or pain. You may need to have blood tests and a chest x-ray to check your general health.

The tests you have will depend on your symptoms. Your doctor and nurse will explain these. They can give you information about any tests not included here.

Ultrasound scan

An ultrasound uses sound waves to make a picture of an area inside the body. You may be asked not to eat or drink for a few hours before the test.

The type of ultrasound will depend on where the lump is in your body.

When you are lying comfortably, the person doing the scan will spread a gel onto the skin over the lump. They pass a small device that produces sound waves over the area. A computer converts the sound waves into a picture. The scan is painless and takes about 15 to 20 minutes.

If the lump is in the womb or pelvis (area between your hips) you may also have a transvaginal ultrasound scan. This is when they gently insert the ultrasound device into the vagina. It gives a very clear picture of the womb and surrounding area.

We have more information at **macmillan.org.uk/ultrasound**

MRI scan

An MRI scan uses magnetism to build up a detailed picture of areas of the body.

The scanner is a powerful magnet. You will be asked to complete and sign a checklist to make sure it is safe for you. This will check whether you have any metal implants, such as a pacemaker or surgical clips. Tell your doctor if you have ever worked with metal. This is because tiny bits of metal can sometimes lodge in the body.

You have the scan in the x-ray department of a hospital. The person who does the scan is called a radiographer. They may give you an injection of a dye called a contrast. This helps show certain areas of the body more clearly.

During the scan, you need to lie still on a bed inside a long cylinder (tube). If you worry about being in small spaces (are claustrophobic), you may be able to have a sedative to help you relax. Talk to your GP or cancer doctor about this before the scan.

The scan usually lasts between 15 minutes and 1 hour. It is painless, but you may find it uncomfortable to lie still for that long.

We have more information about having an MRI scan on our website. Visit **macmillan.org.uk/mri-scan**

CT scan

A CT scan makes a detailed picture of the inside of the body using x-rays taken by the CT scanner. The scan uses radiation, but this is very unlikely to harm you. It will not harm anyone you come into contact with.

You have the scan at the hospital. You will get an appointment letter explaining if you need to do anything before the scan. You should tell the radiographer if you are pregnant or think you could be.

You may have a drink or injection of a dye. This is called a contrast. It helps show certain areas of the body more clearly. The contrast may make you feel hot all over for a few minutes. It is important to tell your doctor if you are allergic to iodine or have asthma. This is because you could have a more serious reaction.

The scan is painless. It usually takes 5 to 10 minutes. The scanner looks like a large, thick ring. You lie still on a narrow bed that moves slowly backwards and forwards through the ring.

Visit **macmillan.org.uk/ct-scan** for more information.

Endoscopy

An endoscopy is a test that looks inside the body using a thin, flexible tube called an endoscope. The tube has a light and video camera at the end so the doctor can see any abnormal areas. It is passed into the body to help doctors see certain areas.

For example, it is passed into the mouth to see the gullet (oesophagus), stomach and small bowel. An endoscopy can be used to investigate GISTs. The doctor may also remove a small sample of tissue (biopsy) during an endoscopy.

Sometimes an endoscopy is combined with an ultrasound. This is called an endoscopic ultrasound scan (EUS).

Having a CT scan

Biopsy

Your doctor or nurse may take samples of tissue from the tumour. This is called a biopsy. It is the only way to tell if the lump is cancer (malignant) or a non-cancerous (benign) tumour.

The samples are sent to a specialist doctor called a pathologist. They have experience in sarcomas. They can tell if the tumour is cancer or not by looking at the cells under a microscope. They do further tests on the sample to try to find out exactly what type of sarcoma it is.

If you are going to have surgery to remove the tumour, you may not have a biopsy before your operation. This may be when the tumour is very small, or it is in the abdomen. Instead, the whole tumour is sent to the laboratory after the operation. The laboratory will do tests to check that it is a sarcoma.

The type of biopsy you have depends on where the lump is, and its size.

Fine needle aspiration (FNA)

Your doctor uses a very thin needle and a syringe to take small pieces of tissue from the lump. An FNA may be slightly uncomfortable but should not be painful. Before the biopsy is taken, you may have an injection of local anaesthetic to numb the area.

The doctor guides the needle to the right place by feeling the lump near the surface of the body. If they cannot feel the lump, or if it is deep inside the body, they may use an ultrasound or a CT scan to guide the needle.

If an FNA does not collect enough cells to give a clear diagnosis, you will need a different type of biopsy.

Core needle biopsy

This is the most common type of biopsy. The doctor uses a hollow needle to take small samples of tissue from the lump.

You are usually awake during a core needle biopsy. You may be given a sedative to make you feel relaxed and drowsy. Sometimes the biopsy is done under a general anaesthetic.

Before the biopsy, the doctor injects a local anaesthetic into the skin around the lump to numb the area. The doctor passes the biopsy needle through the skin and into the lump to take the sample.

You may have an ultrasound or a CT scan at the same time. The pictures from the scan help the doctor guide the needle to the right place. They usually take several samples of tissue.

If the biopsy does not collect enough cells to give a clear diagnosis, you will need a surgical biopsy.

Surgical biopsy

If the lump is small, the doctor may do a small operation to remove the whole lump. This is called an excision biopsy. You may have this done using a local or a general anaesthetic.

Sometimes doctors do a biopsy that removes only a sample of the lump. This type of biopsy is called an incision biopsy. It is done less often than an excision biopsy.

We have more information about biopsies on our website. Visit **macmillan.org.uk/biopsy**

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend.

Your specialist nurse or a support organisation (pages 136 to 147) can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00** (7 days a week, 8am to 8pm).

Further tests

If the tests show that you have a soft tissue sarcoma, your doctor may do further tests. These are to find out the size and position of the cancer and whether it has spread to other parts of the body.

This is called staging (pages 36 to 37). It helps you and your doctor decide on the best treatment for you.

CT scan

You may have a CT scan (page 28) to check your chest. Depending on the type of sarcoma, you may have a CT scan of the abdomen (tummy) or pelvis.

Chest x-ray

This is done to check your general health and to look for any sign that the cancer has spread to your lungs. This is because the lungs are one of the most common places for soft tissue sarcomas to spread to.

PET or PET-CT scan

A PET scan uses low-dose radiation to check the activity of cells in different parts of the body.

You may have a PET scan and a CT scan together. This is called a PET-CT scan. It can give more detailed information about cancer or abnormal areas seen on other scans.

If you are pregnant or breastfeeding, speak to the scanning department before the scan for advice.

About 1 hour before the scan, the radiographer will inject a radioactive substance into a vein, usually in your arm. This is called a tracer. The radiographer will encourage you to drink water. This helps move the tracer around your body.

Very rarely, some people are allergic to the tracer. This can make them feel breathless, sweaty or weak. Tell the radiographer straight away if you feel unwell.

The scan takes about 30 to 60 minutes. The scanner looks like a large, thick ring. You lie still on a narrow bed that moves slowly backwards and forwards through the ring.

The amount of radiation used is very small. But the radiographer will advise you not to have close contact with pregnant people, babies and young children for up to 24 hours after the scan.

We have more information about PET-CT scans on our website. Visit **macmillan.org.uk/pet-ct-scan**

Testing for genetic changes

Tests are done on the tissue samples to find out if there are any genetic changes in the sarcoma cells. This is sometimes called cytogenetic testing.

This can help tell your doctor the type of sarcoma you have and if certain treatments would be suitable for you.

Immunohistochemistry

The tissue sample is tested to look at any proteins the cancer cell is producing.

Grading and staging

The information from your biopsy and tests tells your doctors more about the grade and stage of the cancer.

Grading

The grade of a cancer gives the doctors an idea of how quickly it might grow. Doctors look at a sample of the cancer cells under a microscope to find the grade.

The grade is based on 3 things:

- how normal or abnormal the cells look – this is called differentiation
- how quickly the cells are dividing to make new tumour cells – this is called the mitotic rate
- if there is any dying tissue in the tumour – this is called necrosis.

Doctors use the following 3 grades:

- **G1** cancer cells look much like normal cells. They are usually slow-growing and less likely to spread.
- **G2** cancer cells look different to normal cells. They are slightly faster-growing.
- **G3** cancer cells look very different to normal cells. They can grow more quickly and are more likely to spread.

Staging

The stage of a cancer describes its size and whether it has spread from where it started. Knowing the stage helps doctors decide on the best treatment for you.

Different staging systems may be used. 2 of the most commonly used systems are the TNM and number staging system. Different types of sarcoma use different staging systems.

TNM staging

TNM stands for Tumour, Node and Metastasis.

- **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, such as the lungs or liver. This is called metastatic or secondary cancer.

Doctors put numbers after the T, N, and M to give more details about the size and spread of the cancer.

Number staging

Information from the TNM system and the grade of the cancer can be combined to give a number stage. This list shows number staging of soft tissue sarcomas (STS) that start in the arms, legs or main part of the body (the trunk).

It is divided into 4 stages.

Stage 1 means the sarcoma has not spread to nearby lymph nodes, or other parts of the body. Stage 1 is divided into the following stages:

- **Stage 1A** is 5cm or less, and is grade 1.
- **Stage 1B** is bigger than 5cm and may be over 15 cm. It is either grade 1, or the grade cannot be assessed.

Stage 2 means the sarcoma has not spread the nearby lymph nodes or other parts of the body. Stage 2 is 5cm or less. It is grade 2 or grade 3.

Stage 3 means the sarcoma has not spread to nearby lymph nodes or other parts of the body. Stage 3 is divided into the following stages:

- **Stage 3A** is bigger than 5cm, but not more than 10cm. It is grade 2 or grade 3.
- **Stage 3B** is bigger than 10cm. It may be over 15cm. It is grade 2 or grade 3.

Stage 4 means the sarcoma is advanced. It can be any size and any grade. It has spread to either:

- the lymph nodes nearby
- other parts of the body such as the lungs, liver or bones – this is called secondary or metastatic cancer.

Your doctor or specialist nurse can give you more information about the grade and stage of the sarcoma.

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically.

There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions.

If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out (page 147).

Treating soft tissue sarcoma

Treatment overview

The treatment for soft tissue sarcoma depends on a few things, including:

- the type of sarcoma you have
- where the sarcoma started in the body
- the grade and stage of the sarcoma (pages 35 to 37)
- your general health.

Surgery

Surgery is the most common treatment for soft tissue sarcoma (pages 49 to 74). The operation you have depends on where the sarcoma is in the body. If the sarcoma is small and can be removed completely, surgery may be used on its own.

Some people may need reconstructive surgery using specialist techniques to repair the area of the surgery. It is usually possible to remove a soft tissue sarcoma in an arm or leg without having to remove the whole limb. This is called limb-sparing surgery. It is rare to have the whole limb removed (amputation).

Radiotherapy

Radiotherapy uses high-energy rays to destroy cancer cells. Different types of radiotherapy can be used to treat sarcoma (pages 75 to 85).

For bigger sarcomas, where there is a possibility of cancer cells being left behind, radiotherapy is usually used with surgery.

Radiotherapy may be given:

- before surgery to shrink the cancer
- after surgery, to destroy any remaining cancer cells
- on its own if surgery is not possible, or to treat sarcoma that has already spread (advanced sarcoma).

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. Chemotherapy is not always used to treat sarcoma (page 86). It depends on the type of sarcoma and the risk of it coming back.

It may be given:

- before or after surgery
- if the sarcoma has spread or comes back after treatment (advanced cancer).

Targeted therapy

Targeted therapy drugs (pages 98 to 101) may be used to treat gastrointestinal stromal tumours (GISTs). They may also be used to treat other types of soft tissue sarcoma that have spread or come back after treatment.

Research is going on to find more effective treatments for soft tissue sarcoma. You may be invited to take part in a clinical trial of a new drug or treatment.

We have more information about clinical trials on our website. Visit **macmillan.org.uk/clinical-trials**

How treatment is planned

Because sarcoma is a rare cancer, you should always be referred for treatment at a specialist sarcoma unit.

A team of specialist doctors and other professionals will work together to manage your treatment. This is called a multidisciplinary team (MDT).

It will include the following professionals:

- Surgeon – a doctor who does operations (surgery) and specialises in sarcoma.
- Oncologist – a doctor who treats people who have cancer.
- Clinical nurse specialist (CNS) – a nurse who gives information about cancer, and support during treatment.
- Radiologist – a doctor who looks at scans and x-rays to diagnose problems.
- Pathologist – a doctor who looks at cells or body tissue under a microscope to diagnose cancer.

The MDT may also include healthcare professionals, such as the following:

- Dietitian – someone who gives information and advice about food and food supplements.
- Physiotherapist – someone who gives advice about exercise and mobility.
- Plastic surgeon – a doctor who does operations (surgery) to repair or reconstruct tissue and skin.
- Occupational therapist – someone who gives information, support and aids to help people with tasks such as washing and dressing.
- Psychologist or counsellor – someone who gives advice about managing feelings and behaviours.

Talking about your treatment plan

After the MDT meeting, you will usually see your specialist doctor and nurse. They will talk to you about your treatment plan. It can help to write down your questions before you see them.

You may want to ask a family member or friend to come with you. They can help remember what is said and talk with you about it afterwards. You need to know as much as possible before you can make any treatment decisions.

Your specialist doctor should explain:

- the aim of the treatment – whether it is to cure the cancer or control it
- the benefits of the treatment
- the disadvantages of the treatment – for example, the risks and side effects
- any other treatments that may be available
- what may happen if you do not have the treatment.

Cancer treatments can be complex. It can also be hard to concentrate on what you are being told if you are feeling anxious. If the doctor says something you do not understand, ask them to explain it again.

Most people worry about the side effects of treatment. Your doctor or nurse will explain how side effects can be controlled and what you can do to manage them. They can also tell you if your treatment is likely to cause any late effects and how these can be managed.

You may need more than one meeting with your doctor or nurse to talk about your treatment plan.

Making treatment decisions

You and your doctor can decide together on the best treatment plan for you. Your doctor is an expert in the best treatments. But you know your preferences and what is important to you. You can decide how involved you want to be in your treatment plan.

Sometimes doctors need to review a treatment plan. This may be when more information about the cancer becomes available – for example, when the doctor knows the results of surgery to remove the cancer. It may mean making more decisions with your doctor.

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan.

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision.

You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

Second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your specialist doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your specialist doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website. Visit **macmillan.org.uk/second-opinion**

Surgery

Surgery is the main treatment for soft tissue sarcoma. Soft tissue sarcoma is rare, so surgery is done by a surgeon who specialises in treating it. The surgeon is part of a multidisciplinary team (MDT) and based in a specialist sarcoma unit.

You may have a lump removed and only find out it is a soft tissue sarcoma after the operation. You will be referred to a sarcoma specialist after this first operation.

Before surgery

Depending on the type of surgery you need, you may be referred to a rehabilitation team. They give you advice on how to prepare for surgery and recover from it. They help you to keep the area being operated on working as well as possible.

Before surgery you may be given advice on:

- exercises to help you recover your function after surgery or to get fitter
- stopping smoking to help your recovery and reduce your risk of complications
- eating healthily or taking supplement drinks.

Your surgeon and specialist nurse will discuss your operation and rehabilitation with you.

For more information about giving up smoking, visit **macmillan.org.uk/stop-smoking**

Types of surgery for soft tissue sarcoma

Some operations for sarcoma are minor and remove a small amount of tissue. Others may be more major surgery and could affect how that area of the body works or looks.

Your surgeon and specialist nurse will explain the type of operation that is best for you. They will tell you about possible risks and side effects. They will also be able to answer any questions you have. It is important you understand what your operation may involve.

Wide local excision

The aim of most sarcoma surgery is to remove all of the tumour. Usually, an operation called a wide local excision is done.

This is when the surgeon removes the tumour, along with an area of healthy, cancer-free tissue around it. This area is called a margin.

After the operation, a specialist called a pathologist examines the tissue from the margin. If there are cancerous cells in the margin, you may need another operation to remove more tissue. Making sure the margins are clear reduces the risk of the cancer coming back.

The type of operation you have will depend on where the sarcoma is. You may have other treatments before or after surgery, or both.

Surgery to the chest or tummy (abdomen)

Surgery is usually the main treatment for soft tissue sarcomas in the chest and tummy (abdomen). This area of the body is called the trunk. The type of operation will depend on the position of the tumour. Your surgeon will discuss this with you before the operation.

If the tumour is in the tummy, it can be difficult to remove it along with an area of healthy tissue (margin). This is because the tumour may be very close to important organs, like the kidneys and liver, or main blood vessels.

You may have radiotherapy after an operation to remove a sarcoma in the chest or tummy (pages 75 to 85). This is to try to make sure any remaining cancer cells are destroyed.

Surgery to the arms or legs (limbs)

It is usually possible to remove a soft tissue sarcoma in an arm or leg without having to remove the whole limb. This is called limb-sparing surgery (pages 55 to 63). It is often done by using a combination of surgery, radiotherapy and occasionally chemotherapy.

Rarely, the best treatment option is to remove the affected limb to make sure all the cancer has been removed. This is called amputation.

Surgery to the head and neck

The type of surgery you have depends on the exact position and size of the tumour. Your surgeon will discuss this with you before the operation.

It is important that you understand what is going to be removed and how this will affect you after the operation.

Changes to speech or swallowing

Your surgeon will do everything possible to reduce any effects surgery may have on the way you:

- speak
- swallow
- look.

Sometimes there is a risk your speech, swallowing or eating could be affected for a time after surgery. In this situation you will see a:

- speech and language therapist (SLT), who will teach you exercises to help you communicate
- dietitian, who will give you advice about eating and make sure you get enough nutrition.

They help to prepare you for surgery and continue to support you after surgery.

If the operation involves removing tissue used for speech and swallowing, or affects your appearance, you may have reconstructive surgery at the same time.

A plastic surgeon takes tissue from another part of the body, such as the forearm, thigh or chest. This is used to replace the tissue they take from the head and neck.

Reconstructive surgery

Depending on the size and position of the sarcoma, the surgeon may have to remove a large area of tissue. This may include important nerves and blood vessels.

You may need to have surgery to reconstruct the area. This is done at the same time as your operation, usually by a plastic surgeon.

The aims of reconstructive surgery are to:

- make the area look and work as naturally as possible
- pad and protect important tissue nearby
- help the wound to heal.

The operation will depend on where in your body the sarcoma is and how much tissue the surgeon needs to remove.

If it is a smaller area, the surgeon may be able to join the 2 edges together again. For larger areas, they may need to use a skin graft or tissue flap.

Skin grafts

A skin graft is a very thin layer of skin. The surgeon takes a layer of skin from another part of the body called the donor site. They put this over the area where the cancer was.

Skin is often taken from the outer thigh. If a skin graft is needed for the face, surgeons usually take skin from behind the ear or the neck. This is done to try to get a good skin colour match.

After the operation, you normally have a dressing over the area. This presses the graft down to help create a good blood supply from the blood vessels underneath.

Tissue flaps

Sometimes, plastic surgeons need to use a specialist technique to repair the operation site. They use a slightly thicker layer of skin and tissue than for a skin graft. This is called a tissue flap. Tissue flaps include fat and muscle. The different types of tissue flap include the following:

- A local flap uses tissue from an area close to where the cancer has been removed.
- A pedicle flap uses tissue from an area further away, but close enough to keep the flap connected to its original blood supply.
- A free flap uses tissue that has been completely removed from another part of the body, along with its blood vessels.

The surgeon and specialist nurse will explain your operation and answer any questions you have.

Surgery for secondary tumours

Surgery is sometimes used to remove a sarcoma that has spread to other parts of the body or come back after treatment.

An operation is usually only possible if:

- the tumours are small
- there are only a few tumours.

It is mainly done when the sarcoma has spread to the lungs. But it might be used for tumours in other parts of the body. If you need to have this operation, your doctor will talk to you about it.

Limb-sparing surgery

It is usually possible to remove a soft tissue sarcoma in an arm or leg without having to remove the whole limb. Removing the limb is called amputation (pages 64 to 74).

Surgery that does not remove the limb is called limb-sparing surgery. The surgeon removes the tumour and an area of healthy tissue around it.

Radiotherapy (pages 75 to 85) is often also given:

- before surgery, to try to shrink the tumour
- after surgery, to destroy any remaining cancer cells and reduce the risk of the cancer coming back (adjuvant treatment).

Sometimes, chemotherapy (pages 86 to 97) is given before surgery as well as radiotherapy. You will not have surgery until you recover from chemotherapy. This usually takes about 2 weeks.

> "Initially I was warned that I would have a permanent weakness in that leg. My consultant said a positive attitude can make all the difference, so I took each day as one more step to my recovery. „
>
> Nina, diagnosed with soft tissue sarcoma

Preparing for limb-sparing surgery

Before surgery, your doctor will explain the operation to you, so you fully understand what will happen. You can ask questions about how the surgery might affect you.

A rehabilitation team will help you after the operation (page 61). They work with you to make sure the affected limb works well. This will help you to be as independent as possible after surgery. They also give you information about your recovery. Before surgery, you will meet some of the rehabilitation team.

The team will include specialist doctors and nurses, as well as:

- a physiotherapist
- an occupational therapist (OT)
- a social worker.

We have more information about the people who will support you (pages 44 to 45).

A physiotherapist may talk to you before your operation. They may give you some exercises (page 60) to do before surgery to help strengthen your muscles.

You may find it helpful to talk to someone who has had the same operation in our Online Community. Visit **macmillan.org.uk/community**

They might be able to give you practical advice as well as support. Your healthcare team may be able to arrange this for you.

Some hospitals have a counsellor you can talk to about your feelings and worries before the operation.

After your limb-sparing operation

You may have a drip going into a vein your arm. This is called an intravenous infusion. A nurse will remove it when you are drinking enough.

Your wound

You may have some tubes (drains) to drain fluid from your wound. A nurse will remove these when fluid has stopped draining. This usually takes a few days.

Sometimes, fluid can build up around the wound. The swelling should reduce over a few weeks. Sometimes, a lot of fluid builds up around the wound. This is called a seroma. It may need to be drained by a doctor or nurse.

Your surgeon may use stitches or clips to close your wound. Sometimes they use dissolvable stitches. If you have stitches or clips that need to be removed, you will be told when and where this will happen.

The nurses will monitor the wound for any signs of infection.

Let them know straight away if:

- you feel unwell and have a fever
- there is any warmth, swelling and redness around the wound
- there is discharge from the wound.

Pain

Pain can usually be controlled effectively with painkillers.

They may be given:

- into a vein (intravenously)
- into the space around your spinal cord (epidural)
- into a muscle (intramuscularly)
- as tablets.

To start with, you will probably need a strong painkiller such as morphine. You may be given intravenous pain relief through a syringe connected to an electronic pump. The pump can be set to give you a continuous dose of painkiller.

You may also have a handset with a button you can press if you feel sore. This is called patient-controlled analgesia (PCA). It is designed so that you cannot have too much painkiller (an overdose). That means it is okay to press it whenever you are uncomfortable.

If you have had surgery to the leg, you may have pain relief using an epidural. This is a fine tube inserted through the back into the area around the spinal cord called the epidural space. A local anaesthetic can be given continuously into this space to numb the nerves that run to the legs.

If you are in pain, let your nurses and doctors know as soon as possible. This will help them give you the right combination and dose of painkillers.

Exercises

Your nurses or the physiotherapist will teach you breathing and leg exercises. They encourage you to get up and move around as soon as possible.

Breathing exercises help prevent you getting a chest infection. Leg exercises help stop clots forming in your legs. Chest infections or blood clots can develop if you are not moving around as much as normal. You can help your recovery by doing the exercises as often as you need to.

To help prevent a blood clot in your leg (a deep vein thrombosis or DVT), you may be given elastic stockings to wear. These may be called TED stockings. You may also be given injections of anti-clotting medicines. These help thin your blood and prevent blood clots.

Doing breathing exercises

Rehabilitation

Limb-sparing surgery is a major operation and rehabilitation can sometimes take a long time. It can often be hard work and may be frustrating at times. This will depend on which limb is affected and how big the operation was.

The physiotherapist will show you exercises to help you keep the limb moving and working well. It is important to follow their advice and do the exercises regularly. This will help to reduce the risk of any problems after surgery.

Sometimes, you will need a brace or support for your limb. If the operation was on your leg, you may be given crutches or another walking aid to use while you are learning to walk again.

The rehabilitation team will help you gain as much independence as possible. You may need to make changes to your normal activities. This will depend on the extent of the surgery and how it is affecting you. The occupational therapist (OT) will help you.

Your rehabilitation may take longer if you had radiotherapy (pages 75 to 85) or chemotherapy (pages 86 to 97) before surgery.

Going home

How long you need to stay in hospital after limb-sparing surgery will depend on the operation you had. Your doctor or nurse can give you more information. Sometimes you may need to stay in hospital longer to rehabilitate. This allows you to cope better when you go home.

When you are at home, you will keep having physiotherapy as an outpatient. This can often be done locally to where you live.

Body image

Limb-sparing surgery may cause a change in how your limb looks or works. This may affect how you think and feel about your body. This is called your body image (page 113).

It usually improves as you adapt to any change. But if you still have concerns, talk to your nurse or doctor. They can usually arrange for you to see a psychologist or counsellor for support.

Lymphoedema

After surgery, some people may develop swelling called lymphoedema (page 106). It happens because the lymph nodes and vessels can be damaged by surgery or radiotherapy.

Lymph fluid, which circulates around the lymphatic system, cannot pass along the vessels. It builds up, causing swelling.

There are things you can do to help reduce the risk of lymphoedema. Let your doctor know about any swelling you have after surgery.

> "In the early days after my operation, my lovely friend came and stayed. He kindly offered to work from my dining room table and keep an eye on me."

Nina, diagnosed with soft tissue sarcoma

Amputation

Sometimes it is not always possible to remove the cancer with limb-sparing surgery. Very rarely, the best treatment option is to remove the affected limb. This is called amputation.

It may be done because the cancer is large, or because limb-sparing surgery:

- could affect major blood vessels
- is likely to have a big effect on how the arm or leg works
- could cause long-term pain.

After talking to your cancer doctor and close family or friends, you might decide to have an amputation instead of limb-sparing surgery.

Preparing for an amputation

Before surgery, your doctor and specialist nurse will explain the operation to you. It is important you fully understand what will happen.

You can ask questions about how the surgery might affect you. Your sarcoma team will give you as much support as possible.

A rehabilitation team will help you after the operation (page 69). They work with you to help you to be as independent as possible after surgery. They also give you information about your recovery.

Before surgery, you will meet some of the rehabilitation team. The team will include specialist doctors and nurses, as well as:

- a physiotherapist
- an occupational therapist (OT)
- a prosthetist, who fits an artificial limb (prosthesis) if needed – pages 70 to 74.

They can answer your questions and help with any worries you have about after the operation. They will also talk to you about any changes you need to make to your home. These will make it easier when you go home after surgery.

Getting psychological support is important if you are about to have an amputation. Some hospitals have a counsellor you can talk to about your feelings and worries before and after the operation.

It may also help to talk to someone who has had the same operation. Your healthcare team or keyworker may be able to arrange this for you.

Or you could join our Online Community. Visit **macmillan.org.uk/community**

The Bone Cancer Research Trust website has videos that might also be helpful. Visit **bcrt.org.uk** for more information. There are also organisations that can help (pages 136 to 147).

After your operation

You will usually have a drip to replace your body's fluids. This is called an intravenous infusion. A nurse will remove it when you are drinking enough.

Your wound

To start with, the operated area will be bandaged. You will have a tube in the wound to drain any fluid that builds up. This is removed when fluid has stopped draining. This usually takes a few days.

Sometimes, fluid can build up around the wound. The swelling should reduce over a few weeks. Sometimes, a lot of fluid builds up around the wound. This is called a seroma. It may need to be drained by a doctor or nurse.

Once the bandages have been removed, your physiotherapist or nurse will fit a compression garment. This helps reduce swelling, which can be a problem for some people. You will also be given advice about looking after the scar.

Pain

Pain can usually be controlled effectively with painkillers.

They may be given:

- into a vein (intravenously)
- into the space around the spinal cord (epidural)
- into a muscle (intramuscularly)
- as tablets.

If you are in pain, let your nurses and doctors know as soon as possible. This will help them give you the right amount of painkillers.

Some people have pain that feels like it is coming from the part of the limb that has been amputated. This is called phantom pain or phantom sensation.

This pain usually improves over time, but there may be some discomfort in the area for a while after the operation. Let your nurses and doctor know if you have any phantom pain. They can give you drugs to help control it, such as pregabalin or gabapentin.

Getting up

A physiotherapist or occupational therapist (OT) will help you move around after surgery. This often happens on the first or second day after the operation. It may be hard at first, and you will need to start slowly.

If you have had an arm amputated, you will be able to get up and move around once your pain is controlled and you have recovered from the anaesthetic.

If you have had a leg amputated, the physiotherapist will show you how to move around in bed and how to move into a chair. To start with, you will use a wheelchair. The physiotherapist will help you.

The OT will arrange a wheelchair for you to use in the hospital. You may need the wheelchair at home while you get used to moving around using crutches or an artificial limb.

Before you go home, you will be referred to your local wheelchair service. You will also be given advice about using a wheelchair at home.

Exercises

Your nurses or physiotherapist will teach you exercises for your lungs and limbs. You can help yourself get better by doing the exercises as often as you need to.

The exercises will help prevent you from getting a chest infection and blood clots. Chest infections or blood clots can develop if you are not moving around as much as normal.

To help prevent a blood clot in your leg (a deep vein thrombosis or DVT), you may be given elastic stockings to wear. These may be called TED stockings. You may also be given injections of anti-clotting medicines. These help thin your blood and prevent blood clots.

The physiotherapist will visit you soon after your operation and show you how to do exercises to keep the muscles around the operation site strong and supple. This will make it easier to use an artificial limb (pages 70 to 71).

When you are at home, you will keep having physiotherapy as an outpatient. This can often be done locally to where you live.

Rehabilitation after an amputation

Amputation is a major operation, and rehabilitation can take a long time. It can be hard work and may be frustrating at times.

After the amputation, the occupational therapist (OT) and physiotherapist will help you manage daily activities, such as washing, dressing and using the toilet. They can also recommend equipment to help you be as independent as possible.

The OT and physiotherapist can also give you advice about driving, work and getting back to social activities. They will help you think about how your amputation may affect your life and look at different ways to manage it.

Going home

Before leaving the hospital, your nurse, the physiotherapist and OT will talk to you about how you will manage at home. Together, you need to assess and plan how you will manage your normal daily activities and whether you need any equipment. They may also refer you to your local social services for further assessment.

You may need to make changes to your home and the way you do certain activities. The OT and physiotherapist will help you.

This can sometimes delay you going home from hospital, which may be frustrating. But making sure you can do things safely and independently at home can make a big difference to your recovery.

Artificial limb (prosthesis)

After an amputation, most people can be fitted with an artificial limb. This is called a prosthesis. Modern technology means artificial limbs are now very effective. They allow people to do many of the things they did before the amputation.

Some artificial limbs are designed to look like the limb they are replacing, but do not move. These are often called passive limbs. They usually only replace hands and arms.

Other artificial limbs are designed for a wide range of everyday activities, such as gripping, walking, running and playing sport. These types of limb may look very different from the limb they are replacing. Or they may be designed to look as similar as possible. Depending on your needs, you may have more than 1 type of artificial limb.

Artificial limbs might not be suitable for people who have other health conditions.

Having an artificial limb fitted

After your operation, you will be referred to a prosthetic rehabilitation or limb-fitting unit. The team in the unit will show you the different types of artificial limb and how they work. They will talk to you about your needs and help you choose the best type of artificial limb for you.

When you are ready to have a prosthesis made, a specialist called a prosthetist will take careful measurements or a plaster cast of your limb. They will then make a mould of your limb. This will be used to create a custom-built socket that fits over your limb. The artificial limb is attached to the socket.

It may take a few weeks for your artificial limb to be made. To make sure it fits comfortably, you may need a few fitting appointments.

If it is an artificial leg, you will have specialist physiotherapy for a few months to learn how to use it. If it is an artificial arm, you will have occupational therapy to learn how to use it. You will need to feel well enough to cope with prosthetic rehabilitation. If you are having more treatment after surgery, limb-fitting and rehabilitation may be delayed until you recover.

You will have regular appointments at the limb-fitting unit for the rest of your life. The team in the unit will look after your artificial limb and check it still fits and works properly.

Living with an amputation

Amputation can be very distressing. It can take a long time to come to terms with.

How you might feel

Losing an arm or a leg can feel like a bereavement. You need time to grieve for your loss and to start coping with the emotional and practical difficulties this type of surgery can bring.

We have more information about dealing with the emotional effects of cancer on page 104.

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. You are used to what your body looks like. It can be very difficult to come to terms with a major change such as an amputation.

Feeling that you look different from other people can affect your confidence and how you think and feel about your body (body image).

At first, you may find it difficult to see people after your amputation. But you and the people close to you will get used to the way you look. This will help you become more confident about dealing with the reactions of people you do not know.

Some people find it helpful to get out of the house as soon as possible after their operation. But it is important to take the time you need after surgery to adapt and do things in your own time. You may want to have someone with you when you first go out, to give you emotional support.

Some people might find it helpful to talk with a psychologist or counsellor. Your doctor or nurse can arrange this for you.

We have more information to help you cope with body changes on page 113.

Family and friends

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

But most people find their family and friends want to do as much as possible to support them. It can help to talk about your feelings and any worries you have.

We have more information in our booklet **Talking about cancer**.

Sex and relationships

Some people may feel unattractive and embarrassed about their body. If you have a partner, you may be worried they will not find you attractive. Meeting a new partner may seem scary.

Our booklet **Cancer and your sex life** has more information.

You can order our booklets and leaflets for free.
Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Help is available

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

Many people find it helpful to talk about their feelings with a close friend or someone who is removed from their situation, such as a counsellor.

Our cancer support specialists can talk to you, and tell you how to contact a counsellor or local cancer support group (page 132). You can call them on **0808 808 00 00**.

There are also different organisations that offer support (pages 136 to 147), such as the Limbless Association – visit **limbless-association.org**

Radiotherapy

Radiotherapy uses high-energy rays to destroy cancer cells, while doing as little harm as possible to normal cells. It is an important treatment for soft tissue sarcoma.

Radiotherapy for sarcoma can be given:

- before surgery, to shrink the tumour and make it easier for the surgeon to remove it, or to avoid having to amputate the limb (neo-adjuvant treatment)
- after surgery, to destroy any remaining cancer cells and reduce the risk of the cancer coming back (adjuvant treatment)
- to relieve symptoms and control a sarcoma that has come back after treatment or spread to another part of the body (palliative radiotherapy)
- rarely, on its own as the main treatment.

We have more information in our booklet **Understanding radiotherapy** (page 130). Or visit **macmillan.org.uk/radiotherapy**

How radiotherapy is given

There are different techniques and ways of having radiotherapy for soft tissue sarcoma.

Intensity-modulated radiation therapy (IMRT)

This type of radiotherapy is often used to treat sarcoma. IMRT shapes the radiotherapy beams and gives the tumour a high dose of radiation. It allows different doses of radiotherapy to be given to different areas. Lower doses are given to nearby healthy tissue. This can help reduce immediate side effects and late effects (pages 82 to 85).

Volumetric-modulated arc radiotherapy (VMAT)

VMAT is a newer way of giving IMRT. The radiotherapy machine moves around you and reshapes the beam during treatment. This makes it more accurate and shortens the treatment time.

Stereotactic radiotherapy

This is a new way of giving radiotherapy that may sometimes be used to treat a small soft tissue sarcoma.

You have stereotactic radiotherapy treatment from a specially adapted radiotherapy machine. It gives beams of radiotherapy from many different angles. The beams overlap at the tumour. This gives the tumour a very high dose of radiotherapy. Surrounding tissues only get a very small dose.

Stereotactic radiotherapy is not available in all hospitals in the UK. Your specialist can give you more information if this is an option for you.

Proton beam therapy

Proton beam therapy uses proton radiation to destroy cancer cells, instead of x-rays. Proton beams can be made to stop when they leave the area being treated. This is different to standard radiotherapy beams, which pass through the area and some healthy tissue around it. This means it causes very little damage to nearby healthy tissue and fewer side effects.

It is sometimes used to treat a sarcoma very close to important structures, such as the spine.

Proton beam therapy is given using specialised equipment that is not available in all UK hospitals. You may be referred to another hospital if your cancer doctor thinks it is a suitable treatment for you.

Brachytherapy

Brachytherapy is a type of internal radiotherapy. Doctors treat the cancer by inserting radioactive material directly into the affected area. The tumour gets a high dose of radiation, but healthy tissue only gets a small amount.

Brachytherapy is not commonly used to treat soft tissue sarcoma.

If your specialist thinks brachytherapy will be helpful for you, they will discuss the treatment and its side effects with you.

Intraoperative radiation therapy (IORT)

IORT is a type of internal radiotherapy. It is done during surgery.

After removing the cancer, the doctor gives the same area a single dose of radiotherapy from a special machine. Some people may also have another type of radiotherapy after surgery.

IORT is not suitable for everyone and is not widely available on the NHS.

We have more information about different types of radiotherapy at **macmillan.org.uk/radiotherapy** and in our booklet **Understanding radiotherapy** (page 130).

Planning your radiotherapy

Before you start radiotherapy, the radiotherapy team will plan your treatment. They make sure the radiotherapy is aimed directly at the cancer, causing the least possible damage to nearby heathy tissue. Planning may take a few visits.

Radiotherapy masks and moulds

Radiotherapy moulds may be used to help keep the part of the body having treatment still during treatment. If you are having radiotherapy to your head and neck, you will have a head and neck mould made. If you are having radiotherapy to a limb, you may also need a mould for it.

A radiographer will make the mould on your first visit to the radiotherapy department. Your cancer doctor or specialist nurse will tell you more about moulds if you need one.

The radiographers may use foam blocks or special cushioning bags that are made to fit you to help keep you still during treatment. Cushioning bags may be called vacuum bags. Other devices may also be used to help you to keep still during radiotherapy.

We have more information about radiotherapy masks on our website. Visit **macmillan.org.uk/radiotherapy-masks**

Planning scans

As part of the planning, you will have a CT scan (page 28) of the area to be treated. This helps plan the precise area for your radiotherapy. This session usually takes about 30 minutes.

You may also need to have an MRI scan (page 28). This uses magnetism to build up a detailed picture of part of the body. It can give extra useful information.

The information from the scans goes into the radiotherapy planning computer. The computer precisely designs your individual treatment plan.

Skin markings

To help the radiographers position you accurately for the treatment, they may make marks on your mould or mask. If you do not have a mould or mask, they will make the marks on your skin. These marks must stay throughout your treatment.

Some marks can be washed off when your course of treatment finishes. Other marks may be permanent. These are very small. They will only be made with your permission. It can be uncomfortable while the marks are being made, but only for a very short time.

Having radiotherapy

> “At the beginning of the radiotherapy I was introduced to my Macmillan nurse, who followed my treatment and often phoned and helped with appointments and subsequent questions.”

Herry, diagnosed with soft tissue sarcoma

Treatment sessions

Radiotherapy is normally given as a series of short, daily treatments in the hospital radiotherapy department.

The treatments are usually given every day from Monday to Friday. The number of treatments you have depends on the type, size and position of the area to be treated.

A course of radiotherapy for an early-stage cancer usually lasts about 6 weeks. Each treatment takes about 10 to 15 minutes. Your doctor will talk to you about the treatment and possible side effects.

At the start of each session of radiotherapy, the radiographer will explain what to expect. They will position you carefully on the treatment couch in the same way as during the planning session.

When you are in the right position, the radiographers will leave the room and you will have treatment. Radiotherapy is not painful, but you have to lie still for a few minutes. The radiographers will be able to see and hear you during your treatment.

If you are having stereotactic radiotherapy or proton beam therapy treatment, sessions are usually longer. But you will need fewer sessions than with other types of radiotherapy.

Your doctor, nurse or radiographer will tell you what to expect if you are having these specialised types of radiotherapy.

Side effects of radiotherapy

You may develop side effects during your treatment. These side effects will usually disappear over a few weeks or months after treatment finishes.

Your cancer doctor, nurse or radiographer will explain the ones you are most likely to get, so you know what to expect. They will also talk to you about late effects of radiotherapy. These are side effects that may not go away, or that appear months or years later.

Always tell them about any side effects you have during or after treatment. There are often things that can be done to help.

We have more information in our booklet **Understanding radiotherapy**.

Skin changes

You may find your skin in the treatment area:

- becomes red
- darkens
- feels sore
- feels itchy.

Sometimes the skin gets very sore. It may blister, break or leak fluid. Very rarely, your doctor may stop your treatment for a short time to allow a serious skin reaction to recover.

Skin reactions can take time to improve. They are usually better about 4 weeks after you finish treatment. In the longer term, the area of skin may look or feel slightly different to the surrounding skin. Your radiographers or nurses will give you advice on how to look after your skin during and after treatment.

Tiredness (fatigue)

Tiredness is a common side effect and may continue for months after treatment finishes. Try to get plenty of rest, but balance this with some gentle exercise, such as walking. This can improve your energy levels and help you to feel better.

After your treatment finishes, you can gradually increase your activity.

Our booklet **Coping with fatigue (tiredness)** has more information.

Hair loss

Radiotherapy can make your hair fall out in the area being treated. It may grow back after treatment finishes, but for some people the hair loss is permanent. This depends on how much radiotherapy you have. Your cancer doctor or radiographer can tell you if your hair is likely to grow back after treatment.

We have more information in our booklet **Coping with hair loss**.

Feeling sick (nausea)

If the treatment area is near the tummy and pelvis you may feel sick and sometimes be sick (vomit). Your doctor can prescribe anti-sickness drugs to control this. These are called anti-emetics. Take them as your doctor has prescribed and let them know if a drug is not working. They can prescribe a different anti-sickness drug.

Visit **macmillan.org.uk/nausea-vomiting** for more information.

You can order our booklets and leaflets for free.
Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Long-term side effects of radiotherapy

Some people may have long-term or late effects of radiotherapy. These can develop months or sometimes years after treatment.

Always let your cancer doctor or specialist nurse know if you have any new symptoms or problems after treatment.

Lymphoedema

After radiotherapy, some people may develop swelling called lymphoedema. It happens because the lymph nodes and vessels can be damaged by radiotherapy or surgery.

Lymph fluid, which circulates around the lymphatic system, cannot pass along the vessels. It builds up, causing swelling.

There are things you can do to help reduce the risk of lymphoedema. Let your doctor know about any swelling you have after radiotherapy treatment.

We have more information about lymphoedema in our booklet **Understanding lymphoedema** (page 130).

Stiff joints

Radiotherapy to a joint, such as the knee or elbow, may cause it to become stiff. Talk to your cancer doctor if you notice this.

They can prescribe painkillers to help. It is important to keep the joint mobile by using it and doing regular exercise.

A physiotherapist will give you some exercises to do before, during and after treatment to help prevent stiffness.

Bone changes

Radiotherapy to a limb can increase the risk of breaking (fracturing) a bone in the area. This is rare. Most people who have radiotherapy will not have any bone problems.

If you have pain or aching in the bones, always let your cancer doctor or nurse know. It can be caused by different conditions, but it is very important to get it checked.

Second cancer

A small number of people will develop a second cancer because of their radiotherapy treatment. The chance of developing a second cancer is very small. The benefits of radiotherapy are much greater than the risks.

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells.

Not everyone has chemotherapy. It depends on the risk of soft tissue sarcoma coming back and the type of sarcoma you have.

Chemotherapy may not work well for some types of soft tissue sarcoma. Your doctor can tell you whether chemotherapy is a helpful treatment for you.

It may be given:

- after surgery, to try to reduce the risk of the cancer coming back (adjuvant treatment)
- before surgery, to shrink the tumour and make it easier to remove with surgery (neo-adjuvant treatment).

It may also be used to relieve symptoms and help control sarcoma that cannot be completely removed, or has spread to other parts of the body.

It may help to improve your quality of life. This is called palliative treatment.

Having chemotherapy

The drugs you have can depend on the type of sarcoma. You usually have a combination of drugs, but some are given on their own.

If certain drugs do not work well for you, your doctor may talk to you about trying different ones.

The most commonly used drugs are:

- doxorubicin
- ifosfamide
- liposomal doxorubicin
- gemcitabine
- docetaxel
- paclitaxel
- trabectedin
- dacarbazine
- cyclophosphamide
- vinorelbine.

We have more information about each of these drugs on our website. Visit **macmillan.org.uk/treatments-and-drugs**

How chemotherapy is given

The chemotherapy drugs are usually given by injection into a vein (intravenously). Some drugs can be given as tablets. You have chemotherapy as a session of treatment. You may have chemotherapy as an outpatient. Or you may need to go into hospital for a few days.

Each treatment session is followed by a rest period of a few weeks. This is to allow your body to recover from any side effects.

Chemotherapy and the rest period make up a cycle of your treatment. The number of cycles you have will depend on the type of sarcoma you have and how well it responds to the treatment.

Chemotherapy into a limb

You can sometimes have chemotherapy directly into an arm or leg. It can help control sarcoma that cannot be removed with surgery or has come back in one area. This is called isolated limb perfusion.

Having the drugs directly into the affected limb means that very high doses can be given. The limb is isolated using a tight band. This is called a tourniquet. It stops the chemotherapy drugs going to other areas of the body.

You are unlikely to get common chemotherapy side effects, such as feeling sick. The affected limb may swell and the skin may turn red.

Side effects of chemotherapy

Chemotherapy drugs cause side effects. But there are usually ways these can be controlled.

Your doctor or nurse will give you information about the likely side effects of your treatment. They will also tell you what can be done to control and manage side effects.

Risk of infection

This treatment can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection.

A low white blood cell count is called neutropenia.

An infection can be very serious when the number of white blood cells is low. It is important to get any infection treated as soon as possible.

Contact the hospital straight away on the 24-hour contact number you have been given if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection
- your temperature goes below 36°C (96.8°F).

Symptoms of an infection include:

- feeling shivery
- a sore throat
- a cough
- breathlessness
- diarrhoea
- needing to pass urine (pee) often, or discomfort when you pass urine.

It is important to follow any specific advice your cancer treatment team gives you.

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time, until your cell count increases.

Anaemia (low number of red blood cells)

This treatment can reduce the number of red blood cells in your blood. Red blood cells carry oxygen around the body. If the number of red blood cells is low, this is called anaemia.

You may have symptoms such as:

- pale skin
- lack of energy
- feeling breathless
- feeling dizzy and light-headed.

Tell your doctor or nurse if you have these symptoms. If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

Bruising and bleeding

This treatment can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. If the number of platelets is low, you may bruise or bleed easily. You may have:

- nosebleeds
- bleeding gums
- heavy periods
- blood in your urine (pee) or stools (poo)
- tiny red or purple spots on your skin that may look like a rash.

Tell your doctor if you have any unexplained bruising or bleeding. You may need a drip to give you extra platelets. This is called a platelet transfusion.

Feeling sick (nausea)

Your doctor will give you anti-sickness drugs to help prevent or control sickness during your treatment. Take the drugs exactly as your nurse or pharmacist tells you. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluids often and eat small amounts regularly. It is important to drink enough fluids.

If you continue to feel sick, or are sick (vomit) more than once in 24 hours, contact the hospital as soon as possible. They will give you advice.

Your doctor or nurse may change the anti-sickness drug to one that works better for you.

Sore mouth

This treatment may cause a sore mouth and throat. You may also get mouth ulcers. This can make you more likely to get a mouth or throat infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

If your mouth or throat is sore:

- tell your nurse or doctor – they can give you a mouthwash or medicines to help
- try to drink plenty of fluids
- avoid alcohol, tobacco and foods that irritate your mouth and throat.

> **"I was exhausted all the time because of the treatment. Friends said quite inappropriate things – one friend said I looked good because I'd lost weight. But I'd lost weight because I was on chemotherapy and I hadn't been able to eat anything for 4 days."**
>
> Ruth

Hair loss

Your hair will get thinner. Or you may lose all the hair from your head. You may also lose your eyelashes and eyebrows, as well as other body hair. Hair loss usually starts after your first or second treatment.

Scalp cooling is a way of lowering the temperature of your scalp to help reduce hair loss. Your nurse can tell you if this is an option for you.

Your nurse can talk to you about ways to cope with hair loss. There are ways to cover up hair loss if you want to. Your scalp may be sensitive. It is important to cover your head to protect your skin when you are out in the sun.

Hair loss is almost always temporary. Your hair will usually grow back after treatment finishes.

> **"My hair started falling out so I shaved it off. I found being bald quite liberating but I didn't have any eyebrows or eyelashes. I hated the pitying looks I would get from people, even from older cancer patients in the ward. I think they were pitying me because I was so young."**
>
> Ruth

Feeling tired

Feeling tired is a common side effect of this treatment. It is often worse towards the end of treatment and for some weeks after it has finished. Try to pace yourself and plan your day so you have time to rest.

Gentle exercise, like short walks, can give you more energy. If you feel sleepy, do not drive or operate machinery.

We have more information in our booklet **Coping with fatigue (tiredness)** – page 130.

Effects on the kidneys

This treatment can affect how your kidneys work. This is usually mild and goes back to normal after treatment finishes. You will have blood tests to check how well your kidneys are working.

Tell your doctor or nurse if you have blood in your urine (pee) or you are passing urine less than usual.

It is important to drink at least 2 litres (3½ pints) of non-alcoholic fluid each day to help protect your kidneys.

Numb or tingling hands or feet (peripheral neuropathy)

This treatment may affect the nerves, which can cause numb, tingling or painful hands or feet. You may find it hard to fasten buttons or do other fiddly tasks.

Tell your doctor if you have these symptoms. They sometimes need to lower the dose of the drug. The symptoms usually improve slowly after treatment finishes. But for some people they may never go away. Talk to your doctor if you are worried about this.

Effects on the heart

This treatment can affect how the heart works. You may have tests to see how well your heart is working. These may be done before, during and after treatment.

If the treatment is causing heart problems, your doctor may change the type of treatment you are having.

Fertility

Some cancer drugs can affect whether you can get pregnant or make someone pregnant. If you are worried about this, it is important to talk with your doctor before you start treatment.

It may be possible to store sperm, eggs or embryos for use in the future.

Early menopause

Sometimes chemotherapy treatment causes an early menopause, and they may have symptoms such as hot flushes and sweats.

Hormone replacement therapy (HRT) can often be given to replace the hormones that are no longer being produced. People with a gynaecological sarcoma may not be able to have HRT, because the cancer may be sensitive to hormones.

You may find it helpful to talk about all this with your doctor or a support organisation. You can also talk to one of our cancer support specialists on **0808 808 00 00**.

Contraception

Your doctor will advise you not to get pregnant or make someone pregnant while having this treatment. The drugs may harm a developing baby. It is important to use contraception during your treatment and for a while after treatment finishes.

Your doctor, nurse or pharmacist can tell you more about this.

Targeted therapies

Targeted therapy uses drugs to find and attack cancer cells. There are many different types of targeted therapy, including tyrosine kinase inhibitors (TKIs).

Each type targets something in or around the cancer cell that is helping it grow and survive. They may be used to help treat gastrointestinal stromal tumours (GISTs) – page 16. Or they may be used to control soft tissue sarcoma that has spread.

Targeted therapy drugs may be given as part of a research trial to treat soft tissue sarcoma.

We have more information about research trials in our booklet **Understanding cancer research trials (clinical trials)** – page 130.

Imatinib (Glivec®)

Imatinib is a TKI. It may be used to treat GISTs (page 16), or a rare type of soft tissue sarcoma called dermatofibrosarcoma protuberans. Imatinib works by blocking (inhibiting) signals inside cancer cells.

Blocking the signals stops a series of chemical reactions that make the cells grow and divide. The chemical it blocks is called tyrosine kinase.

It may be given before surgery to shrink a GIST and make surgery more effective. If there is a higher risk of GIST coming back you usually have imatinib for 3 years. This is called adjuvant therapy.

Imatinib may also be given if you have a GIST that cannot be operated on or has spread to other parts of the body. It may help to control it for several years.

You take imatinib once a day as tablets. It can cause side effects such as:

- tiredness (fatigue)
- feeling or being sick
- diarrhoea
- a skin rash
- puffiness, especially around the eyes.

We have more information about imatinib on our website.
Visit **macmillan.org.uk/imatinib**

Sunitinib (Sutent®)

Sunitinib is another TKI. It may be used to treat GISTs that do not respond to imatinib, or if you get a lot of side effects with imatinib.

Sunitinib blocks signals in the cancer cells. This stops a series of chemical reactions that make the cell grow and divide. It also helps stop the tumour developing new blood vessels. Without blood vessels, the tumour cannot get the nutrients it needs to survive.

You take sunitinib as a tablet. Some possible side effects include:

- tiredness (fatigue)
- high blood pressure
- diarrhoea
- sore hands and feet
- a skin rash
- changes to your hair colour
- thyroid changes.

For more information about sunitinib, visit **macmillan.org.uk/sunitinib**

Regorafenib (Stivarga®)

Regorafenib is a newer TKI. It may sometimes be used after imatinib and sunitinib (pages 98 to 99) to treat an advanced GIST that cannot be removed with surgery. It may shrink the tumour or stop it growing for a time. Regorafenib is taken as tablets.

Some possible side effects include:

- an increased risk of infection
- diarrhoea
- feeling and being sick
- thyroid changes
- sore hands and feet
- a skin rash
- changes to your hair colour
- high blood pressure.

For more information, visit **macmillan.org.uk/regorafenib**

Other targeted therapy drugs

Some targeted therapy drugs may only be available in certain situations. Or they may not be widely available throughout the UK.

If a drug is not available to you on the NHS, there may be different ways you can still have it. Your cancer doctor can give you advice.

We have more information about unavailable treatments on our website. Visit **macmillan.org.uk/treatment-not-available**

Pazopanib (Votrient®)

Pazopanib is another TKI. It may be used to treat some types of advanced soft tissue sarcoma that have spread to other parts of the body after having chemotherapy.

It is taken once a day as tablets. Possible side effects include:

- high blood pressure
- diarrhoea
- feeling or being sick
- tiredness (fatigue)
- a skin rash
- changes to your hair colour.

Pazopanib has not been approved by the National Institute for Health and Care Excellence (NICE) or the Scottish Medicines Consortium (SMC) for use on the NHS. Because of this, it may not be widely available.

Crizotinib (Xalkori®)

This drug may be used to treat a rare type of sarcoma called a myofibroblastic tumour. It is not available on the NHS but may be used in certain circumstances. You take it as capsules at home.

Larotrectinib (Vitrakvi®)

Larotrectinib can be used to treat cancers that have a change in a gene called NTRK. But this is not common in sarcoma, so it is rarely used. You have tests on the cancer cells to check for the gene change. You take it as capsules or sometimes as a liquid.

We have more information about these drugs on our website. Visit **macmillan.org.uk/treatments-and-drugs**

Coping with soft tissue sarcoma

Follow-up

After your treatment finishes, you will have regular check-up appointments with your cancer doctor or specialist nurse. You will usually be seen every few months for the first 2 years. Later, you will be seen once a year.

Your cancer doctor and nurse will explain more about your follow-up. It will depend on the type of treatment you had and the risk of the cancer coming back.

Your doctor will examine you. You will usually have regular chest x-rays. Depending on the type of sarcoma you had, you may have other x-rays, CT scans or MRI scans of the area where you had the sarcoma. These check for any signs of the cancer coming back so it can be treated straight away.

You can talk to your doctor or nurse about any problems or worries at these check-ups. But if you notice any new symptoms or have any problems between appointments, contact your doctor or nurse for advice.

Many people find they get anxious before their appointments. You may worry about the cancer coming back. This is natural. It can help to get support from family, friends or your specialist nurse. Or you can speak to our cancer support specialists (page 132).

We have more information in our booklet **Worrying about cancer coming back** (page 130).

Share your experience

When treatment finishes, many people find it helps to talk about it and share their thoughts, feelings and advice with other people.

Your story can be really helpful for other people with a soft tissue sarcoma who may be about to start their treatment. Hearing about how you have coped and how you managed any side effects is very helpful to someone in a similar situation.

If you would like to share your story,
visit **macmillan.org.uk/shareyourstory**

If the cancer comes back

Sometimes, the sarcoma may come back or spread to other parts of the body. The most common area for it to spread to is the lungs. If tests show that you have a small amount of cancer in the lungs, it may be possible to remove the affected part of the lung.

If the cancer comes back somewhere else, your doctor will talk to you about the different treatment options. If the sarcoma has come back in the same area, surgery is the most common treatment.

If the sarcoma has spread to other parts of the body, you usually have chemotherapy. Targeted and immunotherapy drugs may also be used.

Late effects

These are side effects that do not improve, or that develop years after treatment has finished. Your doctor or nurse will explain any likely late effects of your treatment. Not everyone gets late effects. It depends on the treatment you had.

Always tell your doctor if you have any new symptoms, or if side effects are not improving. They will monitor them and arrange for you to have tests, if needed.

Lymphoedema

Lymphoedema is a swelling of a limb or of another area of the body. It sometimes happens after surgery or radiotherapy to the lymph nodes. Lymphoedema may develop months or years after treatment.

There are things you can do to help reduce the risk of lymphoedema.

It is important to protect the skin in the area to reduce the risk of getting an infection. If you have any signs of infection, such as redness or swelling in the treated area, you should see your GP straight away.

Other things you can do are:

- avoid getting cuts or grazes in the area
- keep the skin clean and use a moisturiser every day
- protect the skin from the sun by covering the area.

We have more information in our booklet **Understanding lymphoedema** (page 130). Or visit **macmillan.org.uk/lymphoedema**

Well-being and recovery

After treatment, you may just want to get back to everyday life. But you may still be:

- coping with the side effects of treatment
- adjusting to physical changes
- dealing with some difficult emotions.

Recovery takes time, so do not rush it and try to be kind to yourself.

Some people choose to make lifestyle changes to improve their health and well-being. Even if you had a healthy lifestyle before cancer, you may be more focused on making the most of your health.

This is general advice. It is important to check with your doctor before making any changes to your lifestyle or diet.

Stop smoking

If you smoke, giving up is the healthiest decision you can make.

Smoking is a major risk factor for some cancers, high blood pressure and heart disease. If you want to stop, your GP can give you advice. We have more information about giving smoking on our website. Visit **macmillan.org.uk/stop-smoking**

Drink less alcohol

NHS guidelines recommend that you should not regularly drink more than 14 units of alcohol in a week. It is a good idea to have a few alcohol-free days each week. There is more information about alcohol and drinking guidelines at **drinkaware.co.uk**

Eat a well-balanced diet

Eating healthily will give you more energy and help you to recover.
Try to:

- eat plenty of fresh fruit and vegetables (5 portions a day)
- eat less red meat
- cut down on salt, as it can raise blood pressure and make the kidneys work harder.

Follow any advice you have been given by a dietitian. We have more information in our booklet **Healthy eating and cancer** (page 130).

Keep to a healthy weight

Keeping to a healthy weight reduces the risk of a second cancer. It also cuts the risk of heart and kidney problems and illnesses such as diabetes. Your GP can tell you what the ideal weight for your height is.

If you feel you need to lose weight, ask your GP for advice.

Here are some tips to help you:

- only eat as much food as you need
- eat a balanced diet with lots of fruit and vegetables
- eat less fat and sugar
- be more physically active.

If you have lost weight during treatment, your GP or a dietitian can give you advice about gaining weight.

We have more information in our booklets **Managing weight gain after cancer treatment** and **The building-up diet** (page 130).

> "A side effect of my treatment was really bad fatigue. I used to run, but my pelvis has been weakened. I'm doing swimming now. Overall I'm in a good place."

Ruth

> **"When I was diagnosed, I continued to garden and found it gave me great pleasure and motivation. I have some help now, as I can't get down on the ground or bend too far. But I do as much as I can. „**

Herry, diagnosed with soft tissue sarcoma

Keep active

Exercise has been shown to reduce the side effects of cancer treatment and speed up recovery. Being physically active helps you keep to a healthy weight and can reduce stress and tiredness. It also reduces the risk of other health conditions.

You might want to get back to the type of physical activity you did before your treatment started. Or you might want to try something new. Your sarcoma physiotherapist and occupational therapist can give you advice.

We have more information about being physically active in our booklet **Physical activity and cancer** (page 130).

Reduce stress

Think about ways to reduce the stress in your life. You could make time to do things that you enjoy or that make you laugh. Some people find it relaxing to meditate or to start a new hobby or an evening class. You may find it helpful to write a journal or online blog.

Sex and relationships

Sarcoma and its treatments and side effects may affect your sex life and how you feel about yourself sexually.

Difficulties often slowly improve after treatment. If you have a partner, they may also need time to adjust. Talking about how you both feel is important, as it can help you deal with any fears or worries you may have.

If you want to start a new relationship, it can be difficult to decide what and when to tell a new partner about the cancer. We have more information about this in our booklet **Cancer and relationships: support for partners, families and friends**.

If you are having difficulties with your sex life, talk to your GP. They may be able to refer you to a counsellor or psychologist. Your hospital team or specialist nurse can tell you about sexual health services that are available locally.

The College of Sexual and Relationship Therapists also has a nationwide list of counsellors and therapists. Visit **cosrt.org.uk**

We have more information about how cancer and its treatment can affect your sex life, and what can help, in our booklet **Cancer and your sex life**.

You can order our booklets and leaflets for free.
Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Body image

Sometimes cancer and its treatment causes visible changes to the way you look or how your body works.

These changes can affect the way you think and feel about your body. This is called body image. The changes can also be a reminder of the cancer and treatment. It takes time to get used to a change in appearance.

Everyone adjusts at their own pace and in their own way.

There are things you can do to improve your body image. There are also different ways to get help and support. Your team will give you lots of support before and after treatment.

We have more information in our booklet **Body image and cancer**.

> **"I wasn't dating at the time, once I looked really sick. It was quite hard to deal with. Lots of my friends live in London and I was too sick to travel down to see them, so they'd come up for the weekend but we'd have early nights. I felt like an old person."**
>
> Ruth

What you can do

One of the hardest things to cope with can be the feeling that the cancer and its treatment have taken over your life. This is a common feeling, but there are lots of things you can do.

There may be days when you feel too tired to even think about what could help. You will have good and bad days, but if you are overwhelmed by these feelings, let your doctor or nurse know.

If you have depression, they should be able to help.

Finding ways to cope

You may find it helps to try to carry on with life as normally as possible, by staying in contact with friends and keeping up your usual activities.

Or you may want to decide on new priorities in your life. This could mean spending more time with family, going on the holiday you have dreamed about or starting a new hobby. Just thinking about these things and making plans can help you realise that you still have choices.

Some people want to improve their general health by eating a healthier diet, getting fitter or finding a relaxing complementary therapy.

Understanding the cancer and its treatment helps many people cope. It means they can discuss plans for treatment, tests and check-ups with their doctors and nurses. Being involved in these choices can help give you back control of your life.

Complementary therapies

Some people find that complementary therapies can reduce symptoms and help them feel better. It is important to discuss your planned therapy with your specialist or GP to check if there are any reasons why you should not do it. Many doctors are now comfortable with medical and complementary therapies being used together.

Many hospitals and hospices offer complementary therapies. Treatments may include acupuncture, massage, aromatherapy and relaxation techniques.

Therapies such as gentle massage can be done by a partner, family member, friend or carer. This can help them support you.

We have more information about complementary therapies on our website at **macmillan.org.uk/complementary-therapies** and in our booklet **Cancer and complementary therapies** (page 130).

Your feelings and relationships

Your feelings

It is common to have many different feelings when you are told you have cancer. You may feel shocked, scared, depressed, guilty or angry. This can be difficult to cope with. Partners, family and friends may also have some of the same feelings.

We have more information about emotions on our website and in our booklet **How are you feeling? The emotional effects of cancer** (page 130).

Your healthcare team will usually give you support. But you may feel you need more help. Talk to your cancer doctor, GP or specialist nurse. They can refer you to a specialist doctor, psychologist or counsellor who can help.

You can also call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists.

Talking to family, friends or other people affected by cancer may help. For more information or for help finding local support groups, visit **macmillan.org.uk/supportgroups**

Or talk to other people on our Online Community at **macmillan.org.uk/community**

There is more information on pages 132 to 135 about other ways we can help you.

Relationships

Cancer and its treatment are stressful and may affect your relationships. Your experience of cancer may strengthen your relationships with people close to you. Or it may put a strain on relationships. Any problems usually improve over time, especially if you talk openly with each other.

We have more information about relationships online and in our booklets **Talking about cancer** and **Cancer and relationships: support for partners, families and friends**.

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You can support the person with cancer by listening and talking with them.

We have more information about supporting someone on our website and in our booklet **Talking with someone who has cancer**.

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers on our website and in our booklet **Looking after someone with cancer**.

Talking to children and teenagers

Deciding what to tell children or teenagers about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. It may be best to start by giving them small amounts of information, and then tell them more when they are ready.

Use simple, straightforward language to explain what is happening. You can encourage them to talk to someone they trust, who can support them. They may also find support online.

The website **riprap.org.uk** offers information and support for teenagers who have a parent with cancer.

We have more information in our booklet **Talking to children and teenagers when an adult has cancer**.

You can order our booklets and leaflets for free.
Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Work and financial support

Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to. We also have information for carers (page 130).

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- **gov.uk** if you live in England or Wales
- **socialsecurity.gov.scot** if you live in Scotland
- **nidirect.gov.uk** if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to them by calling the Macmillan Support Line on **0808 808 00 00**. Please note the opening times may vary by service.

You can also get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland (pages 141 to 142).

Our booklet **Help with the cost of cancer** has lots more information (page 130).

Macmillan Grants

Macmillan Grants are small, mostly one-off payments to help people with the extra costs that cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing or help paying heating bills, you may be able to get a Macmillan Grant. A grant from Macmillan does not usually affect the benefits you are entitled to. It is an extra bit of help, not replacement for other support.

To find out more, or to apply, call us on **0808 808 00 00** or visit **macmillan.org.uk/grants**

Insurance

If you have or have had cancer, you may find it hard to get certain types of insurance.

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on **0808 808 00 00**.

We have more information in our booklet **Travel and cancer** (page 130). Our Online Community forum on travel insurance may also be helpful. Visit **macmillan.org.uk/community**

Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager or human resources (HR) department soon after you are diagnosed. This will help them to support you better.

Your cancer doctor, GP or specialist nurse can help you decide whether you should go back to work, and when.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful.

You can also find out more about your employment rights in our booklet **Your rights at work when you are affected by cancer**.

There is also lots more information online at **macmillan.org.uk/work**

You can order our booklets and leaflets for free. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Further information

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more booklets or leaflets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**

If you would like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

The language we use

We want everyone affected by cancer to feel our information is written for them.

We try to make sure our information is as clear as possible. We use plain English, avoid jargon, explain any medical words, use illustrations to explain text, and make sure important points are highlighted clearly.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary, we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected. Our aims are for our information to be as clear and relevant as possible for everyone.

You can read more about how we produce our information at **macmillan.org.uk/ourinfo**

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. We can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Our trained cancer information advisers can listen and signpost you to further support. Call us on **0808 808 00 00**. We are open 7 days a week, 8am to 8pm.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to **macmillan.org.uk/talktous**

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line.

Call **0808 808 00 00** and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we will arrange for an interpreter to contact you.

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with energy costs

Our energy advisers can help if you have difficulty paying your energy bills (gas, electricity and water). They can help you get access to schemes and charity grants to help with bills, advise you on boiler schemes and help you deal with water companies.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to find out more about Macmillan Grants.

Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, family member or friend, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

You can also use our Ask an Expert service on the Online Community. You can ask a financial guide, cancer information nurse, work support advisor or an information and support advisor any questions you have.

Macmillan healthcare professionals

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

Sarcoma support organisations

GIST Cancer UK

Tel **0300 400 0000**
www.gistcancer.org.uk
A network of patients and carers, providing information and support to anyone affected by a GIST.

Sarcoma UK

Tel **020 7856 0445**
Helpline **0808 801 0401**
www.sarcoma.org.uk
Offers support and information to anyone affected by sarcoma. The website has information about various types of sarcoma, as well as links to support groups and helpful videos.

General cancer support organisations

Cancer Black Care

Tel **020 8961 4151**
www.cancerblackcare.org.uk
Offers UK-wide information and support for people from Black and minority ethnic communities who have cancer. Also supports their friends, carers and families.

Cancer Focus Northern Ireland

Helpline **0800 783 3339**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline **0808 800 4040**
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Cancer Support Scotland

Tel **0800 652 4531**
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Children's Cancer and Leukaemia Group (CCLG)

Tel **0333 050 7654**
www.cclg.org.uk
Supports and funds research into childhood and teenage cancers.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices
A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's

Tel **0300 123 1801**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 3000 118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Riprap

www.riprap.org.uk
Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.

Tenovus

Helpline **0808 808 1010**
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

General health information

Health and Social Care in Northern Ireland

www.northerntrust.hscni.net
Provides information about health and social care services in Northern Ireland.

NHS 111 Wales

111.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88**
www.nhsinform.scot
NHS health information site for Scotland.

NHS.UK

www.nhs.uk
The UK's biggest health information website. Has service information for England.

Patient UK

www.patient.info
Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health-related and illness-related websites.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'Therapist Directory' page.

UK Council for Psychotherapy (UKCP)

Tel **020 7014 9955**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

College of Sexual and Relationship Therapists (COSRT)

Tel **020 8106 9635**
www.cosrt.org.uk
Provides information about sexual wellbeing, including having therapy and finding a therapist. Its website has a list of professional therapists.

Mind

Helpline **0300 123 3393**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **116 123**
Email **jo@samaritans.org**
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**
Textphone **028 9031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Carer's Allowance Unit

Tel **0800 731 0297**
Textphone **0800 731 0317**
www.gov.uk/carers-allowance
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use its online webchat or find details for your local office by contacting:

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

Civil Legal Advice

Helpline **0345 345 4345**
Textphone **0345 609 6677**
www.gov.uk/civil-legal-advice
Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English is not your first language.

Disability and Carers Service

Tel **0800 587 0912**
Textphone **0800 012 1574**
nidirect.gov.uk/contacts/disability-and-carers-service
Manages Disability Living Allowance, Attendance Allowance, Carer's Allowance and Carer's Credit in Northern Ireland. You can apply for these benefits and find information online or through its helplines.

GOV.UK

www.gov.uk
Has information about social security benefits and public services in England, Scotland and Wales.

Equipment and advice on living with a disability

British Red Cross

Tel **0344 871 11 11**
www.redcross.org.uk
Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Disability Rights UK

Tel **0330 995 0400** (not an advice line)
www.disabilityrightsuk.org
Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

Limbless Association

Tel **0800 644 0185**
www.limbless-association.org
Provides information, advice and support to people of any age, whether they are about to have an amputation or have already lost a limb. Also supports carers, family and friends.

Living Made Easy

Helpline **0300 999 0004**
www.livingmadeeasy.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.

Motability Scheme

Tel **0300 456 4566**
www.motability.co.uk
The scheme enables disabled people to exchange mobility allowances they have as part of benefits (including the enhanced rate mobility component of Personal Independence Payment) to lease a new car, scooter or powered wheelchair.

Support for young people

Teenage Cancer Trust

Tel **0207 612 0370**
www.teenagecancertrust.org
A UK-wide charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for young people with cancer, their friends and families.

Young Lives vs Cancer

Tel **0300 330 0803**
www.younglivesvscancer.org.uk
Provides clinical, practical, financial and emotional support to children with cancer and their families in the UK.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030**
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Live Through This

www.livethroughthis.co.uk
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage.
Also produces resources about LGBT cancer experiences.
Live Through This runs a peer support group with Maggie's Barts.

Support for carers

Carers Trust

Tel **0300 772 9600**
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline (England, Scotland, Wales) **0808 808 7777**
Helpline (Northern Ireland) **028 9043 9843**
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

Cancer registries

The cancer registry is a national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

National Cancer Registration and Analysis Service (England)

digital.nhs.uk/ndrs/patients

Scottish Cancer Registry and Intelligence Service (SCRIS)

Tel **0345 646 0238**
beta.isdscotland.org/topics/scottish-cancer-registry-and-intelligence-service-scris

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **02920 104278**
phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu

Northern Ireland Cancer Registry

Tel **0289 097 6028**
www.qub.ac.uk/research-centres/nicr

Your notes and questions

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date, but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor, Dr Fiona Cowie, Consultant Clinical Oncologist.

With thanks to: Dr Charlotte Benson, Consultant Medical Oncologist; Professor Mark Bower, Consultant Medical Oncologist; Lynsey Green, Clinical Specialist Sarcoma Physiotherapist; Dr Jenny Sherriff, Consultant Clinical Oncologist; Ariana Silva, Sarcoma Clinical Nurse Specialist; Mr Ian M Smith, Consultant Plastic Surgeon; and Dr James Wylie, Consultant Clinical Oncologist.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories. This includes Herry, who has sadly died. We thank his family for allowing us to continue sharing his story, so others can benefit from Macmillan's support.

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

Sources

Below is a sample of the sources used in our soft tissue sarcoma information. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Casali PG, Blay JY et al. Gastrointestinal stromal tumours: ESMO-EURACAN-GENTURIS Clinical practice guidelines for diagnosis, treatment and follow-up. Annals of Oncology, 2022; 33,1, 20–33 [accessed May 2022].

Gronchi A, Miah AB et al. Soft tissue and visceral sarcomas: ESMO-EURACAN-GENTURIS Clinical practice guidelines for diagnosis, treatment and follow-up. Annals of Oncology, 2021; 32, 11, 1348–1365 [accessed May 2022].

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 ways you can help someone with cancer

1. **Share your cancer experience**
   Support people living with cancer by telling your story, online, in the media or face to face.

2. **Campaign for change**
   We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

3. **Help someone in your community**
   A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

4. **Raise money**
   Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

5. **Give money**
   Big or small, every penny helps. To make a one-off donation see over.

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number
☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Valid from ☐☐ ☐☐

Expiry date ☐☐ ☐☐

Issue no ☐☐☐

Security number ☐☐☐

Signature

Date / /

Do not let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

☐ I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

If you would rather donate online go to **macmillan.org.uk/donate**

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REGULATOR

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ

This booklet is about soft tissue sarcoma. It is for anyone who has been diagnosed with a soft tissue sarcoma. There is also information for carers, family members and friends.

The booklet talks about the signs and symptoms of a soft tissue sarcoma. It explains how it is diagnosed and how it may be treated. It also has information about feelings, practical issues and money.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

Trusted Information Creator
Patient Information Forum