A practical guide to understanding cancer

UNDERSTANDING SOFT TISSUE SARCOMAS

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 family members and friends.

The booklet explains what soft tissue sarcomas are, and how they are diagnosed and treated. It also has information about the feelings you might experience, and how your relationships, work and finances might be affected.

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

The 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.

Quotes

Throughout this booklet, we have included quotes from Herry, Nina and Ruth who have had a soft tissue sarcoma. Some quotes are from our Online Community (**macmillan.org.uk/community**). The others are from people who have chosen to share their story with us. 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**, Monday to Friday, 9am 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, call **0808 808 00 00** or visit **macmillan.org.uk/otherformats**

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Ruth, diagnosed with soft tissue sarcoma

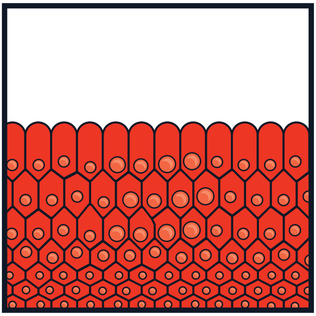
ABOUT SOFT TISSUE SARCOMAS

What is cancer?

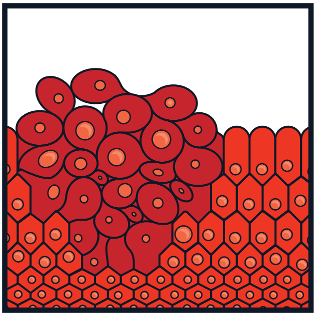
Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop growing. When a cell is no longer needed or can't 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). 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. The doctors examine the sample under a microscope to look for cancer cells.

Normal cells



Cells forming a tumour



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.

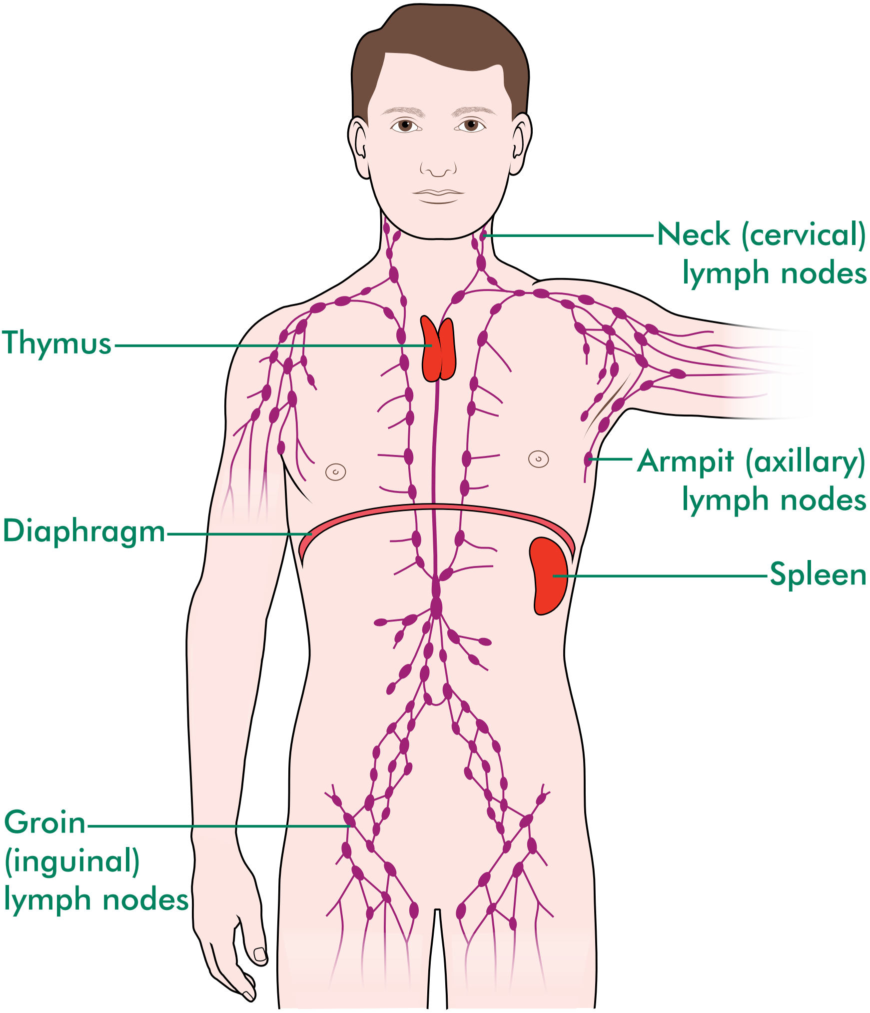
A lump that is cancer (malignant) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or lymphatic system. When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a secondary cancer or a metastasis.

The lymphatic system

The lymphatic system helps to 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 up of fine tubes called lymphatic vessels that connect to groups of lymph nodes throughout the body.

Lymph nodes (sometimes called lymph glands) 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 are soft tissue sarcomas?

Sarcomas are rare. Each year, about 3,300 people in the UK are diagnosed with a soft tissue sarcoma.

Soft tissue sarcomas are cancers that develop from cells in the supporting tissues of the body. They can develop in any tissues that support, connect, surround and protect the organs of the body. This includes:

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

Soft tissue sarcomas can develop anywhere in the body. The most common parts of the body for them to develop are the arms and legs. Nearly half of all soft tissue sarcomas develop there. They can also develop in organs such as the womb (uterus), stomach, skin and intestines. Or they can develop in the area in the back of the tummy (abdomen), called the retroperitoneum. Less commonly, they can develop in the head and neck.

Some types of sarcoma can develop in children, teenagers and young adults. But they are more likely to develop in people over the age of 30.

Bone sarcomas

Some sarcomas, such as osteosarcoma, start in the bone. They grow, develop and are treated differently from soft tissue sarcomas. Sometimes it is hard to tell whether a sarcoma has started in soft tissue or bone. Some types of sarcoma, such as Ewing tumours, can start in either the bone or the soft tissue.

We have separate information about cancer that starts in the bone in our booklet **Understanding primary bone cancer** (see page 138).

Types of soft tissue sarcoma

There are many types of soft tissue sarcoma, and they usually grow and develop differently from each other. We describe the most common types in this information. Your doctor or specialist nurse can tell you more about the type of soft tissue sarcoma you have.

Each type of sarcoma is named after the type of cell it started from. It is not named after the part of the body where it started to grow.

Fat tissue tumours

Sarcomas that start in the body’s fat cells are called **liposarcomas**. They 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.

Liposarcomas are more commonly diagnosed in people aged 50 to 65. Some grow very slowly, taking many years to develop. Others grow more quickly.

Muscle tissue tumours

There are two types of muscle tissue in the body – **smooth** and **skeletal**.

Smooth muscle sarcomas

Smooth muscle makes up the walls of internal organs such as the womb (uterus), stomach, intestines and blood vessels. The muscle makes these organs contract. This happens without our control, so smooth muscle is also called involuntary muscle.

Sarcomas that develop in smooth muscle are called **leiomyosarcomas (LMS)**. They are one of the more common types of sarcoma.

Leiomyosarcomas can develop anywhere in the body. They are most common in the tummy, retroperitoneum and pelvic area. Sometimes they are found in the deep, soft tissues of the arms or legs.

Leiomyosarcomas usually develop in adults, particularly older people. They are most commonly diagnosed in people over the age of 50.

We have more information about leiomyosarcomas on our website (see page 138).

Skeletal muscle sarcomas

Skeletal muscles are the active muscles in our arms and legs, and other parts of the body. We control these muscles, so they are also called voluntary muscles. Sometimes they are called striated muscles, because the cells look stripy under a microscope.

Sarcomas that develop in skeletal muscles are called **rhabdomyosarcomas (RMS)**.

Skeletal muscle sarcomas are most common in the head and neck. But they can also develop in organs such as the bladder, the vagina and the arms or legs.

Rhabdomyosarcomas are most commonly diagnosed in children.

We have more information about rhabdomyosarcomas on our website (see page 138).

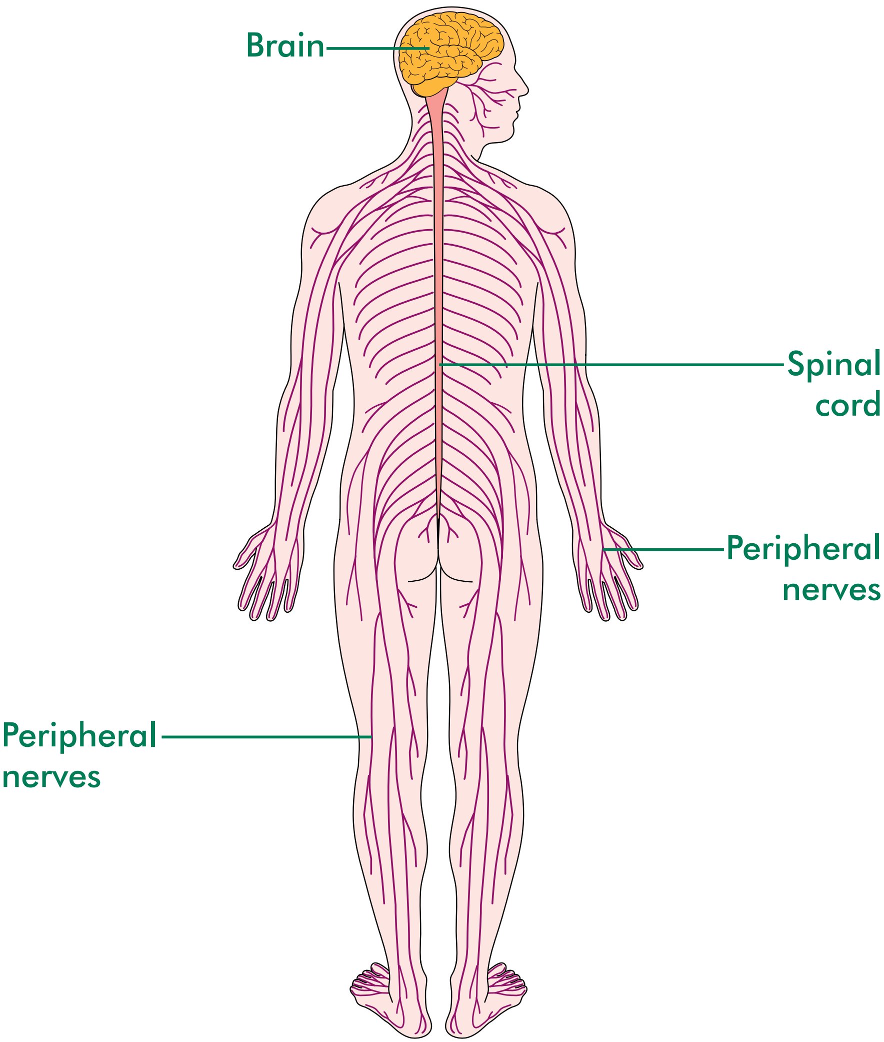
Peripheral nerve tumours

The body's nervous system is divided into two 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.

Sarcomas of the peripheral nerves develop in the cells that cover the nerves. They are called **malignant peripheral nerve sheath tumours (MPNST)** and can develop anywhere in the body. There are different types of MPNST. They are most commonly diagnosed in people aged 30 to 50, who have a rare genetic disorder called neurofibromatosis (von Recklinghausen's disease).

The nervous system



Fibrous tissue tumours

Fibrous tissues join together the inner structures of the body. 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 of fibroblastic sarcoma.

Undifferentiated pleomorphic sarcoma

Soft tissue sarcomas can usually be accurately diagnosed as a certain type. This is based on the type of cell the sarcoma starts from. But sometimes it is not clear which cell the sarcoma starts from. This type of sarcoma is known as an undifferentiated pleomorphic sarcoma (UPS). This type of sarcoma used to be called a malignant fibrous histiocytoma (MFH), however this name is used less often.

Undifferentiated pleomorphic sarcomas are more commonly diagnosed in people aged 60 to 70. They can affect any part of the body, but most commonly develop in the legs and arms.

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) in older people.

Fibrosarcoma

This is a rare type of fibrous tissue sarcoma. It most commonly develops in the arms, legs, central part of the body (trunk) and head and neck. But it can also develop deeper in the body. It can develop at any age, but it is more commonly diagnosed in middle-aged and older adults.

Dermatofibrosarcoma protuberans (DFSP)

These are rare, slow-growing tumours. They usually start in the skin and are usually diagnosed in people aged 20 to 30.

Fibromatosis

These tumours are sometimes known as Desmoid tumours. They are classified as benign tumours, not cancer. Desmoid tumours do not usually spread to other parts of the body, but they can spread into nearby tissues and cause damage. This means they are usually treated in a similar way to cancerous sarcomas.

Blood and lymph vessel tumours

Sarcomas that start from the cells that make up the walls of blood or lymph vessels are called **angiosarcomas**. There are two types of angiosarcoma:

- haemangiosarcomas develop from blood vessels
- lymphangiosarcomas develop from lymph vessels.

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

Other types of soft tissue sarcoma

Synovial tumours

These tumours can develop anywhere in the body, but are often found close to joints and tendons. They are common around the knee, hip and ankle. They are usually diagnosed in people aged 15 to 35, but can develop in people of any age.

Gastrointestinal stromal tumours (GISTs)

These are the most common type of soft tissue sarcoma. They develop in nerve cells in the walls of the digestive system. The digestive system is often called the gastrointestinal (GI) tract. This type of tumour may also be called GI stromal sarcoma.

A GIST behaves differently from other types of sarcoma and is treated very differently.

We have more information about GISTs on our website (see page 138).

Kaposi's sarcoma (KS)

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

KS can affect people with a weakened immune system. This includes people with HIV and Aids. Other types of KS can affect people of Jewish, Italian and West African origin.

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

We have more information about Kaposi's sarcoma on our website (see page 138).

Soft tissue Ewing sarcoma

Ewing sarcoma is a rare type of cancer that usually develops in the bones. Sometimes Ewing sarcoma starts in the soft tissues of the body. This is called extraosseous Ewing sarcoma (extra means outside, osseous means bone), or soft tissue Ewing sarcoma. Ewing sarcoma is most commonly diagnosed 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.

You might find our booklet called **Understanding primary bone** cancer helpful (see page 138).

Rarer types of soft tissue 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 on **0808 808 00 00**.

Soft tissue sarcomas in children

Soft tissue sarcomas can develop in children, particularly some types of rhabdomyosarcoma. Their symptoms and the treatment they are given may be different from an adult with the same sarcoma.

We have more information about children's cancers on our website. This includes information about the types of sarcoma in children and how they are treated. See page 138 for details.

Risk factors and causes

The causes of soft tissue sarcomas are not known, but research is happening to try to find out more. There are certain things that can affect the chances of developing a soft tissue sarcoma. These are called risk factors. Having a risk factor does not necessarily mean you will get sarcoma, and people without risk factors can still develop it.

Age

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

Genetic conditions

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

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

- neurofibromatosis
- retinoblastoma
- Li-Fraumeni syndrome.

You normally know if you have one of these genetic conditions. Your doctor can tell you about any symptoms of sarcoma that you need to look out for.

Your family might have a strong history of lots of different types of cancer, such as breast and bowel cancer. Research has shown that this may mean you may have an increased risk of developing a soft tissue sarcoma.

We have more information in our booklet **Cancer genetics – how cancer sometimes runs in families** (see page 138).

Previous radiotherapy treatment

Very rarely, a soft tissue sarcoma develops in a part of the body that has previously been treated with radiotherapy for another type of cancer. The sarcoma does not usually develop until at least 5 to 10 years after the radiotherapy treatment. To reduce this risk, radiotherapy is very carefully planned. Improvements in the way radiotherapy is given mean the risk of developing a sarcoma after having it is very small.

Lymphoedema

Long-term swelling in an arm or leg, called lymphoedema, can increase the risk of developing an angiosarcoma (see page 17).

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

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

We have more information in our booklet **Understanding lymphoedema** (see page 138).

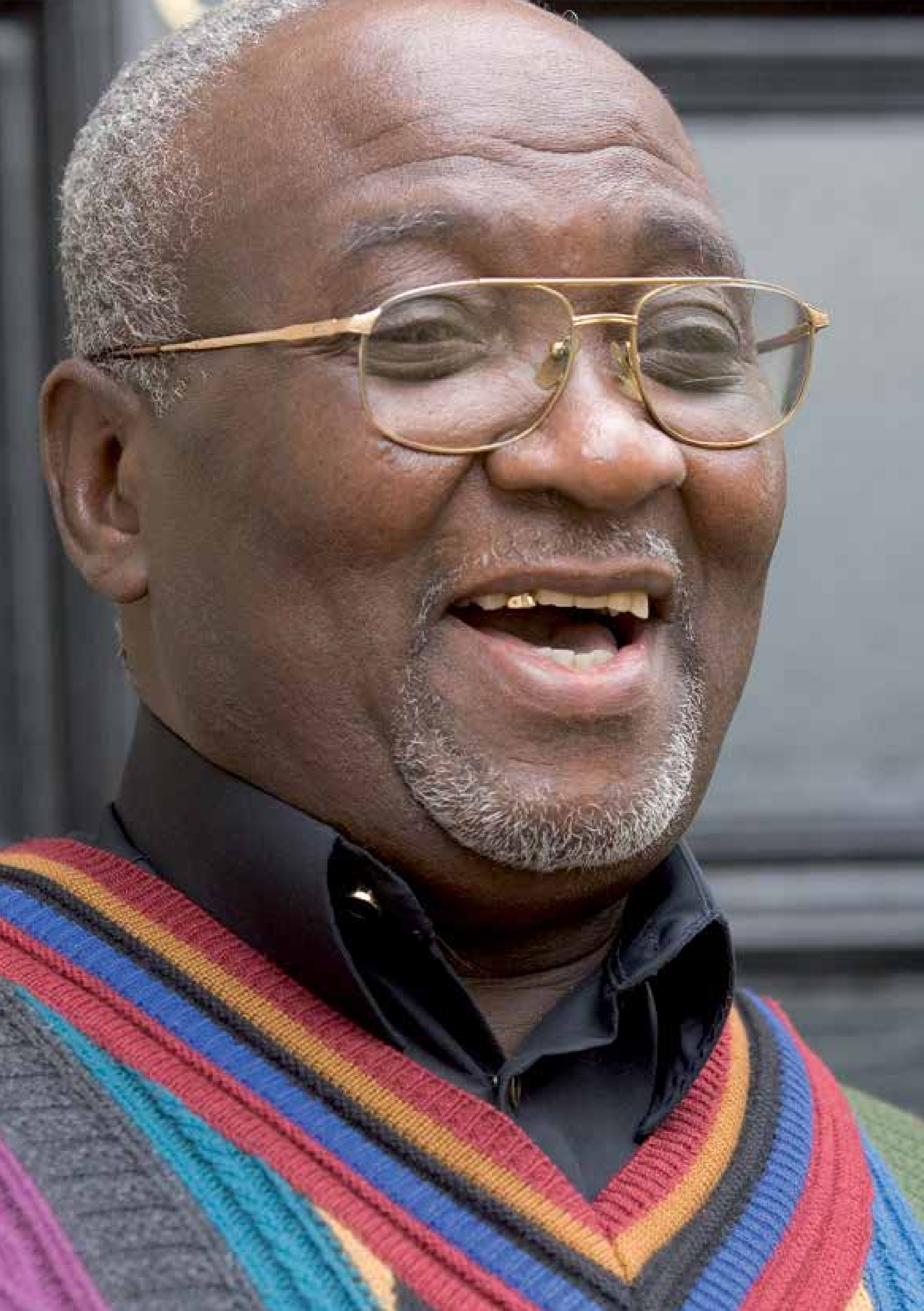
Exposure to chemicals

The development of some sarcomas may be linked to exposure to some types of chemical. These include:

- vinyl chloride – this is used for making plastics
- some types of weed killer (herbicide)
- dioxins – these are waste products made during the manufacture of chemicals and fertilisers.

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.



DIAGNOSING SOFT TISSUE SARCOMAS

Symptoms of soft tissue sarcomas

Soft tissue sarcomas can start in any part of the body. The symptoms depend on the part of the body that is affected. Often, soft tissue sarcomas do not cause any symptoms until they are quite large and pressing on an organ, nerve or muscle in the body.

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.

Symptoms of a sarcoma in an arm or a leg

If there is a sarcoma in an arm or a leg, the most common symptom is an uncomfortable swelling in the affected limb.

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

Symptoms of a sarcoma in the central part of the body

If there is a sarcoma in the central part of the body (the trunk), the symptoms depend on which of the body's organs is affected. For example, you may:

- have a cough and breathlessness if there is a sarcoma in a lung
- have tummy (abdominal) pain, vomiting and constipation if there is a sarcoma in the tummy
- vomit blood or have dark coloured poo if there is a gastrointestinal stromal tumour (GIST) – this is because of bleeding in the bowel
- have symptoms of a low number of red blood cells (anaemia), such as shortness of breath and tiredness if there is a GIST – this is also caused by bleeding in the bowel
- have bleeding from the vagina and pain in the lower part of the tummy if there is a sarcoma in the womb.

How soft tissue sarcomas are diagnosed

You usually start by seeing your GP, who will examine you. They may arrange for you to have tests, such as 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 will usually be seen at the hospital within 2 weeks.

At the hospital

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

The following tests are commonly used to diagnose a soft tissue sarcoma. The tests you have will depend on the part of the body being investigated. You may have had some of these tests already. Our cancer support specialists or your specialist doctor or nurse can give you information about any tests we do not explain here (see page 138 for details).

Ultrasound scan

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

When you are lying comfortably on your back, a gel is spread on to the area being examined. A small device that produces soundwaves is passed over the area. A computer converts the soundwaves into a picture. The scan is painless and takes about 15 to 20 minutes.

If you have a lump in your tummy (abdominal lump), you may have an abdominal ultrasound.

If the lump is in the womb, the ultrasound device may also be gently inserted into the vagina. This is called a transvaginal ultrasound scan. It gives a very clear picture of the womb, which allows the doctor to examine it closely.

If the lump is in a limb, you may also have an ultrasound scan of the area.

> ‘As part of a routine check-up I was referred for an ultrasound. I had other tests before being diagnosed with a grade 3 soft tissue sarcoma. It was large and deep but thankfully hadn’t spread.’
>
> **Simon**

Biopsy

Your doctor or nurse may take samples of tissue from the tumour. The samples are looked at under a microscope. This is called a biopsy. It is the only way to tell whether the lump is a cancerous (malignant) or non-cancerous (benign) tumour. You may have other tests and scans to assess the lump before a biopsy.

A biopsy can be done in different ways:

- a fine needle aspiration (FNA)
- a core needle biopsy
- a surgical biopsy.

The samples are sent to a specialist doctor (pathologist). The pathologist can tell whether the tumour is a cancer or not by looking at the sample of cells under a microscope. If a sarcoma is diagnosed, they may do further tests on the sample to try to find out exactly what type of sarcoma it is. This is called cytogenetic testing.

If you are going to have surgery to remove the tumour, you may not have a biopsy taken before your operation. Instead, the whole tumour is sent to the laboratory after the operation for tests to confirm that it is a sarcoma.

Fine needle aspiration (FNA)

Your doctor uses a very thin needle and a syringe to withdraw small pieces of tissue from the lump. They can often guide 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.

An FNA may be slightly uncomfortable, but should not be painful. You may have a local anaesthetic injection to numb the area before the biopsy is taken.

Sometimes an FNA does not provide enough cells to give a clear diagnosis and a different biopsy is needed.

Core needle biopsy

This is similar to an FNA, but the doctor uses a bigger needle. Before the biopsy, you have a local anaesthetic injection in the skin around the lump to numb it. The doctor then passes the biopsy needle through the skin and into the lump to take the sample. They use a special needle to do this. They may take several samples.

Sometimes the doctor uses an ultrasound or a CT scan to guide the needle to the right place.

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

For most people, a core needle biopsy shows whether the lump is cancerous (malignant) or non-cancerous (benign). But sometimes it does not provide enough cells to give a clear diagnosis. If this happens, you will need a surgical biopsy.

Surgical biopsy

This type of biopsy is done less often. It may be useful if the results of a needle biopsy are unclear, or if the lump is deep inside the body.

The surgeon uses a surgical knife (scalpel) to open the affected area and remove a sample from the lump. This is called an **incision biopsy**. Sometimes, if the lump is small, the doctor removes the whole lump. This is called an **excision biopsy**.

You will be given a local or a general anaesthetic before a surgical biopsy. This depends on your general health, the size of the tumour and how deep it is inside the body.

Waiting for 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 can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

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 (see pages 38 to 41). It helps you and your doctor decide on the best treatment for you.

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.

MRI scan

This test uses magnetism to build up a detailed picture of areas of your body. The scanner is a powerful magnet so you may be asked to complete and sign a checklist to make sure it is safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins, etc.

You should also tell your doctor if you have ever worked with metal or in the metal industry as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body, it is likely that you will not be able to have an MRI scan. In this situation, another type of scan can be used. Before the scan, you will be asked to remove any metal belongings including jewellery.

Some people are given an injection of dye into a vein in the arm, which does not usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly. During the test, you will lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It is painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It is also noisy, but you will be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.

CT scan

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10 to 30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with.

You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. It is important to let your doctor know if you are allergic to iodine or have asthma, because you could have a more serious reaction to the injection.

You will probably be able to go home as soon as the scan is over.

Having a CT scan

PET scan

PET scans can be used to accurately define the cancer and find out if it has spread to other parts of the body. PET scans can also be used to examine any lumps that remain after treatment to see if they are scar tissue or whether cancer cells are still present.

A PET scan uses low-dose radioactive glucose (a type of sugar) to measure the activity of cells in different parts of the body. The scan may help to find out if a tumour is growing and whether it is cancerous (malignant) or non-cancerous (benign).

A very small amount of a mildly radioactive substance is injected into a vein, usually in your arm. A scan is then taken a couple of hours later. Cancer cells are usually more active than surrounding tissue, and show up on the scan.

Not all hospitals have PET scanners. If you need one, you may have to travel to another hospital.

Waiting for 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 one of the organisations listed on our database can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

Grading and staging

The information from your biopsy, scans and other test results tells your doctors more about the grade and stage of the cancer. This information is used by a team of doctors and nurses called a multidisciplinary team (MDT) – see page 44. Your MDT will decide on the most appropriate treatment for you.

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 of the cancer.

Grading of soft tissue sarcomas can sometimes be difficult. The grade is based on three 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.

There are three grades:

- **G1** – the cancer cells look like normal cells, are usually slow-growing and are less likely to spread.
- **G2** – the cancer cells look different to normal cells and are slightly faster growing.
- **G3** – the cancer cells look very different to normal cells, may 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. Two of the most commonly used systems are the TNM and number staging system.

T N M staging

T stands for Tumour

T describes the size of the tumour.

N stands for Nodes

N describes whether the cancer has spread to the lymph nodes

M stands for Metastasis

M describes whether the cancer has spread to another part of the body, such as the liver or lungs (known as metastatic or secondary cancer).

Doctors put numbers after the T, N, and M that 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 used to give a number stage. The number stages vary slightly depending on where in the body the cancer started.

Soft tissue sarcomas are usually divided into four stages:

Stage 1 soft tissue sarcomas have not spread to lymph nodes or other parts of the body. Stage 1 is divided into two stages.	
Stage 1A	• The cancer is smaller than 5cm, and either it is low grade or the grade is not known.
Stage 1B	• The cancer is bigger than 5cm, and either it is low grade or the grade is not known.
Stage 2 soft tissue sarcomas have not spread to lymph nodes or other parts of the body.	
Stage 2	• The cancer is smaller than 5cm, and it is either moderate or high grade.
Stage 3 soft tissue sarcomas are divided into two stages.	
Stage 3A	• The cancer is bigger than 5cm but not bigger than 10cm. It is either moderate or high grade, and it has not started to spread.
Stage 3B	• The cancer is bigger than 10cm. It is either moderate or high grade, and it has not started to spread. **or** • The cancer is of any size and grade, and it has spread to at least one lymph node. It has not spread to any other parts of the body.

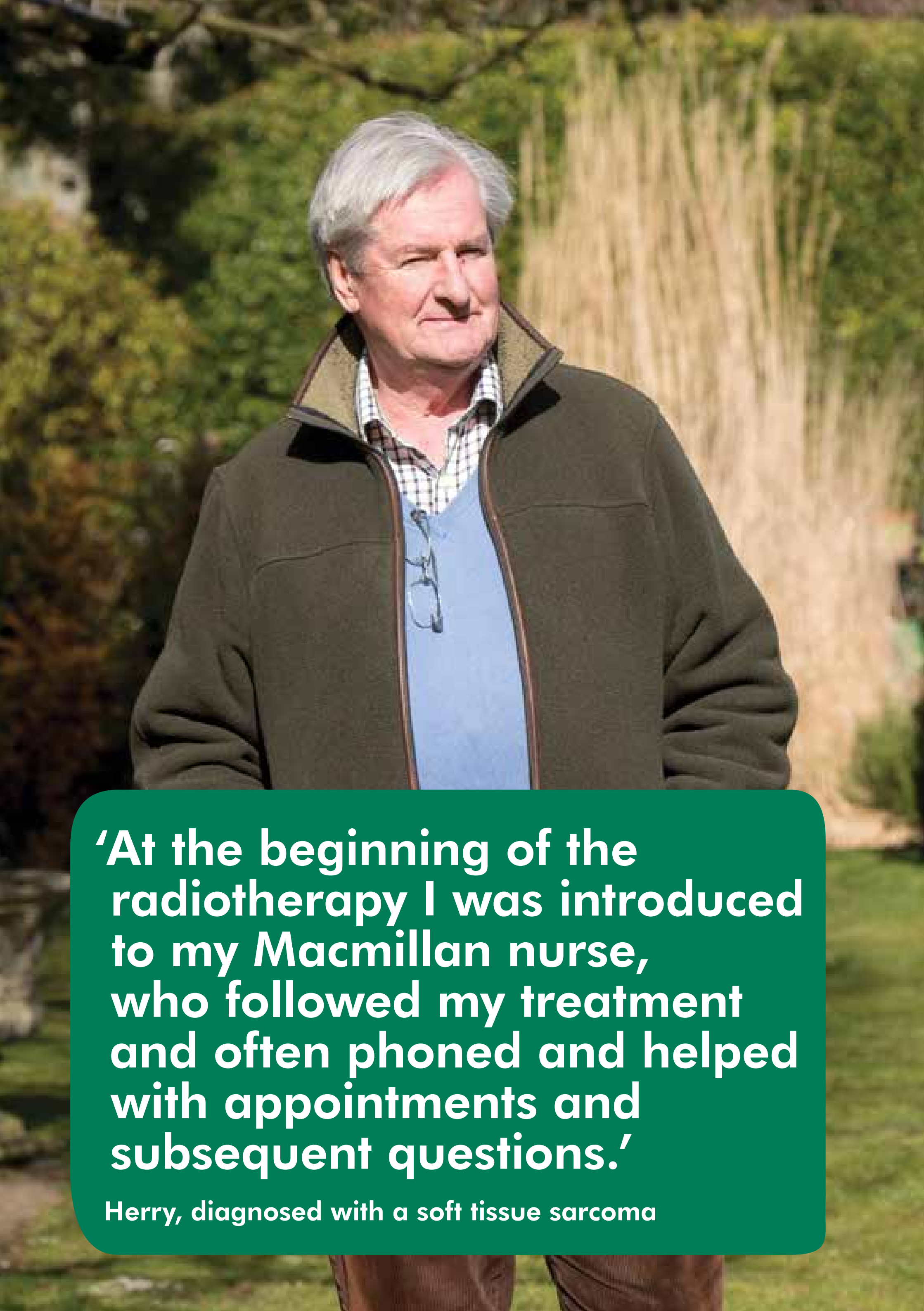
Stage 4 soft tissue sarcomas.	
Stage 4	• The cancer is of any size and grade. It may or may not have spread to lymph nodes. But it has spread to another part of the body such as the lungs, liver or bones. This is called secondary or metastatic cancer.

Your doctor or specialist nurse can give you information about your grade and stage.

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you and your health 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. You can find more information at **macmillan.org.uk/cancerregistry**



> ‘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 a soft tissue sarcoma

TREATING SOFT TISSUE SARCOMAS

How treatment is planned

Because sarcomas are rare cancers, 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 specialises in sarcomas.
- **Oncologist** – a doctor who specialises in cancer treatments such as chemotherapy, radiotherapy and targeted therapy.
- **Specialist nurse** – a nurse who gives information and support about any aspect of your illness or treatment.
- **Radiologist** – a doctor who specialises in reading scans and x-rays.
- **Pathologist** – a doctor who specialises in looking at cells under a microscope and diagnosing the cell type.

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

- **Dietitian** – someone who advises you on how to get all the nutrients your body needs.
- **Physiotherapist** – someone who can help if you have problems moving around.
- **Plastic surgeon** – a surgeon who is skilled in rebuilding tissue.
- **Occupational therapist** – someone who makes sure you are safe and comfortable at home. For example, they can suggest and arrange minor changes to the home.
- **Psychologist or counsellor** – someone who can help you cope with any emotional difficulties.

Treatment overview

The treatment for soft tissue sarcomas depends on a number of things, including:

- your general health
- where the cancer started in the body
- the size of the tumour
- the grade of the cancer (see pages 38 to 41).

The results of your tests will help your doctors plan the best type of treatment for you (see pages 28 to 32). They will then discuss this with you.

Surgery is the most common treatment for soft tissue sarcomas (see pages 51 to 78). If the sarcoma is small and it is possible to remove it completely, surgery may be used on its own.

For bigger sarcomas, and where there is a possibility of cancer cells being left behind, radiotherapy is usually used as well as surgery (see pages 79 to 87). Radiotherapy uses high-energy rays to destroy cancer cells. Radiotherapy may be given:

- before the operation, to shrink the tumour and make it easier to remove
- after surgery, to try to destroy any cancer cells that may not have been removed
- on its own or in combination with chemotherapy to treat more advanced sarcomas and sarcomas that cannot be completely removed (see pages 89 to 96).

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. Chemotherapy may sometimes be given:

- before surgery, to shrink the tumour
- after surgery, to try to destroy any cancer cells that have not been removed
- if the sarcoma has spread or comes back after treatment (advanced cancer).

Targeted therapy drugs (see pages 98 to 101) may be used to treat gastrointestinal stromal tumours (GISTs) – see page 18. Targeted therapies may also be used to treat other types of soft tissue sarcoma that have spread or come back after treatment.

Treatment given before surgery is called neo-adjuvant therapy. Treatment given after surgery is called adjuvant therapy.

Research is going on to find more effective treatments for soft tissue sarcomas. You may be invited to take part in a clinical trial of a new drug or treatment (see pages 102 to 103).

Talking about your treatment plan

After the MDT meeting, your cancer doctor or specialist nurse will talk to you about your treatment options.

They will explain the main aims of treatment. These may be to try to cure the cancer, to help you live longer or to relieve symptoms. They will also tell you the possible short-term and long-term side effects of the treatments.

Deciding which treatments are right for you is usually a joint decision between you and your cancer team. Cancer specialists have expert knowledge of the treatments, but you know your situation, beliefs and preferences.

If one treatment has been shown to work best, you may be happy to be guided by your cancer doctor. But there can be times when the choice of treatment depends on your preferences.

If a cure is not possible and the aim of the treatment is to control the cancer, it may be more difficult to decide what to do. You may need to discuss this in detail with your doctor. If you choose not to have the treatment, you can still be given supportive (palliative) care to control any symptoms.

Making treatment decisions

When you are making treatment decisions, it is important to talk about things carefully with your healthcare team. It can help to make a list of the questions you want to ask. You can take this to your next appointment. It can also be helpful to have a family member or close friend with you at appointments. You may choose to keep notes about what has been said (see page 152) for space to write things down).

It is important that you ask your doctors and nurses any questions you have about your treatment. The more you understand, the easier it will be for you.

You might find our booklet **Making treatment decisions** helpful (see page 138).

Giving consent

Before you have any treatment, your doctor will explain its aims. They will ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment.

No medical treatment can be given without your consent.

Before you are asked to sign the form, you should be given full information about:

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you don't understand what you've been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it's not unusual to need repeated explanations.

It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion.

You may also find it useful to write a list of questions before your appointment.

People sometimes feel that hospital staff are too busy to answer their questions, but it's important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

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

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

Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion. Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

Surgery

Soft tissue sarcomas are rare, so surgery is done by a surgeon who specialises in treating them. 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 surgery. In this situation, you will be referred to a sarcoma specialist who is part of an MDT after your initial surgery.

The aim of most sarcoma surgery is to remove all of the tumour. Usually, an operation called a **wide local excision** is done. This means the surgeon removes the tumour, along with an area (margin) of healthy, cancer-free tissue around it.

After the operation, the 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.

Types of surgery for soft tissue sarcoma

It is difficult to give general information about sarcoma surgery, because the type of operation you have will depend on where in your body the sarcoma is. In this information, we explain the types of surgery used for people with a soft tissue sarcoma in different parts of the body.

Some types of surgery for sarcoma are minor and only involve removing a small amount of tissue. Some operations are major and may affect how that area of the body works, or how it looks.

Before surgery, you may be referred to a rehabilitation team (see pages 65 to 66). They will help you recover from the operation and keep as much function as possible. If the surgery is very minor, you may not need the help of the rehabilitation team.

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

Surgery to the chest or tummy (abdomen)

Surgery is usually the main treatment for soft tissue sarcomas in the chest and tummy. The chest and tummy area of the body is called the trunk. The type of surgery you have will depend on the exact 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 and an area of healthy tissue (margin). This is because the tumour may be very close to vital organs.

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

> ‘The tumour needed to be removed. To get to it, part of two of my ribs were removed. I am now being monitored every 3 months and seem to be progressing well.’
>
> **Simon**

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 (see pages 59 to 66). It is often done by using a combination of surgery, radiotherapy and occasionally chemotherapy.

Very rarely, the best treatment option is to remove the affected limb (amputation) – see pages 68 to 78.

> ‘They called me in and told me it was cancer. From there, my treatment plan was decided. It was quite scary because the cancer can lead to amputation. The position of the cancer, on my right knee, meant it was a risk.’
>
> **Jessica**

Surgery to the head and neck

Surgery is one of the main treatments for soft tissue sarcomas in the head and neck area. The type of surgery you have will depend 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, both in the short-term and long-term.

There may be a risk your speech, swallowing or eating could be affected for a time after surgery. If this may happen, you will meet a speech and language therapist (SLT) or dietitian before and after the operation. Your surgeon will do everything possible to minimise the changes surgery may cause to your appearance, speech and swallowing.

If the operation involves removing tissue that is used for speech and swallowing, or affects your appearance, you may have reconstructive surgery as part of the operation (see pages 56 to 57). This is when the surgeon takes tissue from another part of the body, such as the forearm, thigh or chest, and uses it to replace the tissue they take from the head and neck.

We have more information about surgery for a head and neck cancer in our booklet **Understanding head and neck cancers** (see page 138).

Reconstructive surgery

Depending on the size and position of the tumour, the surgeon may have to remove a large area of tissue. This area may include important nerves and blood vessels. You may need to have surgery to reconstruct the area. The reconstruction will be done at the same time as your operation.

The aim of reconstructive surgery is to make the area look and work as naturally as possible. The exact surgery you have will depend on where in your body the sarcoma is and how much tissue the surgeon needs to remove. If only a small area needs been removed, the surgeon may be able to join the two edges together again. But 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 (often a plastic surgeon) takes a layer of skin from another part of the body (the donor site). Then they put it over the area where they removed the cancer from.

The outer thigh is a common place to take the skin from. But a skin graft for the face is usually taken from behind the ear or the neck area. This is done to try to get a good skin colour match.

After the operation, you normally have a dressing over the area to press the graft down. This helps 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, which includes fat and muscle. This is called a tissue flap. There are several different types:

- 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 to you 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 and there are only a few of them. It is mainly done when the sarcoma has spread to the lungs, but may 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 (amputation). The surgeon removes the tumour and an area of healthy tissue around it.

Radiotherapy is often also given (see pages 79 to 87):

- before surgery, to try to shrink the tumour
- after surgery, to destroy any cancer cells that may still be in the area – it is very difficult to be completely certain that all the cancer cells were removed during the operation.

Your doctor will talk to you about the best options.

Sometimes, chemotherapy (see pages 89 to 96) is given before surgery instead of radiotherapy. If you have chemotherapy, you may have side effects. You will not have the operation until any side effects get better. This usually takes about 2 weeks.

Preparing for limb-sparing surgery

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

You will meet some of the rehabilitation team who will help you after the operation. They will help you keep as much function as possible in the affected limb. This is so you can be as independent as possible after the surgery. They will also give you information about your recovery.

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

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

A physiotherapist may talk to you before your operation. They may give you some exercises to do before surgery to help strengthen your muscles (see page 63).

You may find it helpful to talk to someone who has had the same operation. They might be able to give you practical advice as well as support. Your healthcare team or your keyworker 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.

> ‘I had the surgery and I was in the hospital for a week. I couldn’t believe it when they took out the whole tumour.’
>
> **Hayley**

After your limb-sparing operation

You may have a drip (intravenous infusion) going into your arm to replace your body's fluids. This can be removed as soon as you are drinking enough.

Your wound

You may have some tubes (drains) to drain fluid from your wound. This usually takes a few days. These are removed when fluid has stopped draining.

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 known as 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 that is 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). So, it is okay to press it whenever you are uncomfortable.

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

Let your nurses and doctors know as soon as possible if you are in pain. This will help them give you the combination and dose of painkillers that is right for you.

We have more information in our booklet **Managing cancer pain** (see page 138).

Exercises

Your nurses or the physiotherapist will teach you breathing and leg exercises. You can help yourself get better by doing the exercises as often as you need to. They will also encourage you to get up and move around as soon as possible.

Breathing exercises will help prevent you from getting a chest infection. Leg exercises will help stop clots forming in your legs. 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 (TED stockings) to wear. You may also be given injections of anti-clotting medicines to help thin your blood.

> ‘When I woke up after surgery I was determined to walk. They gave me crutches and I hobbled about. I was in hospital for three days and then I went back home.’
>
> **Jessica**

> ‘Initially I was warned that I would have a permanent weakness in that leg. I like to think it’s my grit and determination that means I haven’t now.’

Nina, diagnosed with a soft tissue sarcoma

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 as much function as possible in the limb. 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 after the limb-sparing surgery. 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 OT will help you.

Your rehabilitation may take longer if you had radiotherapy or chemotherapy before surgery.

Going home

How long you need to stay in hospital after limb-sparing surgery will depend on the type of operation you have had. Your doctor or nurse can tell you how long they think it might be. Sometimes you may need to stay in hospital longer to rehabilitate. But this will allow you to cope better when you go home.

If you think you might have problems when you go home, tell your nurse or social worker when you are admitted to the ward. For example, it may be difficult if you live alone or you have several flights of stairs to climb. They can arrange help before you leave hospital.

Your physiotherapist will arrange for you to continue having physiotherapy when you go home. This will usually be as an outpatient, and can often be arranged for somewhere local to where you live.

Help is available

Some people take longer than others to recover from their operation. If you have any problems, you may find it helpful to talk to someone who is not directly involved with your situation. Our cancer support specialists can talk to you, and tell you how to contact a counsellor or local cancer support group. You can call them on **0808 808 00 00**.

‘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 a soft tissue sarcoma

Amputation

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 (amputation). This may be because:

- the cancer is large
- limb-sparing surgery could affect major blood vessels
- there is a high risk limb-sparing surgery will greatly affect how the arm or leg works
- limb-sparing surgery could cause long-term pain.

After discussing everything with your cancer doctor, and close family or friends, you might choose to have an amputation instead of limb-sparing surgery.

Preparing for an amputation

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

Before the operation, you will meet the rehabilitation team who will help you after the operation. 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.

They can answer any questions or concerns about how you will manage after the operation. They will also talk to you about any changes you may need to make to your home. These will make it easier for you 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 the operation.

It may also help to talk to someone who has had the same operation. They may be able to give you practical advice as well as support. Your healthcare team or your keyworker may be able to arrange this for you.

After your operation

You will usually have a drip (intravenous infusion) to replace your body’s fluids. This can be removed as soon as 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 off 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.

Let your nurses and doctors know as soon as possible if you are in pain. This will help them give you the combination and dose of painkillers that is right for you.

Some people have a pain that feels like it is coming from the part of the limb that has been amputated. This is known as **phantom pain** or **phantom sensation**. This pain usually fades 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.

We have more information in our booklet **Managing cancer pain** (see page 138).

Exercises

Your nurses or the physiotherapist will teach you breathing and leg exercises. 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 (TED stockings) to wear. You may also be given injections of anti-clotting medicines to help thin your blood.

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 (see below).

Your physiotherapist will arrange for you to continue having physiotherapy when you go home. This will usually be as an outpatient, and can often be arranged for somewhere local to where you live.

Getting up

A physiotherapist or occupational therapist (OT) will help you get up. This often happens on the first or second day after the operation. It may feel difficult at first, and you will need to start slowly.

If you have had a leg removed, 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 to get around. Within a few days you may also be able to start using elbow crutches or a walking frame. The physiotherapist will help you.

The OT will arrange for you to have a wheelchair 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. So 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.

Rehabilitation

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 OT will help you manage your day-to-day activities, such as getting washed, dressed and using the toilet. They can show you techniques and recommend equipment to help you be as independent as possible.

The OT 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 living 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.

Artificial limb (prosthesis)

After an amputation, most people can be fitted with an artificial limb 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. But because the arm and particularly the hand are very complex and do many different tasks, prosthetic arms are less technically advanced than legs.

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

Other artificial limbs are designed to allow 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 one type of artificial limb.

Using an artificial limb uses up more energy, so they might not be suitable for people who are frail or have other health conditions like heart disease.

Having a prosthesis 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 prosthesis and how they work. They will talk through your needs, and help you choose the best type of prosthesis for your situation.

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

It may take several weeks for your artificial limb to be made. To make sure it fits comfortably, you may need a few fitting appointments. It is important to tell the prosthetist how well the artificial limb fits and works.

If it is a leg prosthesis, you will have specialist physiotherapy for several months to learn how to use it. If it is an arm prosthesis, 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 usually have regular appointments at the limb-fitting unit for the rest of your life. The team in the unit will look after your prosthesis and check it is still fitting and functioning properly.

Living with an amputation

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

Your feelings and emotions

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

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

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. This may be because the full realisation of having lost an arm or leg hits you. You are used to what your body looks like, and it can be very difficult to come to terms with a major change such as an amputation.

Feeling like you look different from other people can affect your self-confidence. At times, you may even wish you had never had the operation.

It can often be more difficult to adjust to losing an arm than a leg. A prosthetic leg can often be covered by wearing trousers, and a prosthetic arm cannot be covered so easily.

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 also help you become more confident about dealing with the reactions of people you do not know.

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

We have more information to help you cope with body changes in our booklet **Body image and cancer** (see page 138).

Family and friends

Your partner, family and friends may also find it hard to come to terms with their feelings about your amputation. You may be anxious about what they will say or think, and whether you will be able to cope with their reactions. But most people find their family and friends want to do as much as possible to support them. It can help to be open about your feelings and any fear of rejection.

We have more information to help you in our booklet **Talking about cancer** (see page 138).

Sexuality

You may feel unattractive and embarrassed about your body. If you have a partner, you may be concerned that they will not find you attractive any more. Meeting a new partner may seem particularly scary.

We have more information on sexuality and cancer in our booklets **Cancer and your sex life - information for women** and **Cancer and your sex life - information for men** (see page 138).

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 discuss 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. You can call them on **0808 808 00 00**.

Being positioned for radiotheray

Radiotherapy

Radiotherapy uses high-energy rays to destroy cancer cells, while doing as little harm as possible to normal cells. Radiotherapy is an important part of treatment for soft tissue sarcomas. It can be given in different ways:

- It can be given after surgery (**adjuvant treatment**), to destroy any remaining cancer cells and reduce the risk of the cancer coming back. The wound must be healed before radiotherapy starts.
- It can be given before surgery (**neo-adjuvant treatment**), either to shrink the tumour and make it easier for the surgeon to remove it successfully, or to avoid having to amputate the limb.
- It can be given to help relieve symptoms and control a sarcoma that has come back after treatment or spread to another part of the body and cannot be removed. This is called **palliative radiotherapy** and may help improve your quality of life.
- Rarely, radiotherapy is given on its own and may be the only treatment needed.

How radiotherapy is given

Intensity-modulated radiation therapy (IMRT)

This type of radiotherapy is often used to treat sarcomas. IMRT gives the tumour a high dose of radiation and changes the dose given to nearby healthy tissue. This can help reduce side effects.

Intraoperative radiation therapy (IORT)

This type of radiotherapy is given from inside the body (internally) during surgery.

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

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

We have more information about internal radiotherapy in our **Understanding radiotherapy** booklet (see page 138).

Stereotactic radiotherapy

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

Stereotactic radiotherapy treatment is given using 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, and 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.

Brachytherapy

Brachytherapy is when doctors treat the cancer by inserting radioactive material directly into the affected area. A high dose of radiation is given to the tumour, but healthy tissue only gets a small amount of radiation. Brachytherapy is not commonly used to treat soft tissue sarcomas.

Your specialist can discuss brachytherapy and its side effects with you if they think it will be helpful.

We have more information about brachytherapy in our **Understanding radiotherapy** booklet (see page 138).

Proton beam therapy

Proton beam therapy uses proton radiation rather than x-rays to destroy cancer cells. Proton beams can be made to stop when they reach the area being treated. This is different to standard radiotherapy beams, which pass through the area and then continue through the body. Using proton beam radiotherapy may help to reduce damage to surrounding healthy tissues.

Proton beam therapy is sometimes used to treat sarcomas in children and sarcomas in adults that are very close to important structures, such as the spine.

Proton beam therapy will be available at the Christie Hospital in Manchester from late 2018. It will also be available at University College Hospital in London from 2020. The Department of Health can sometimes arrange for people who need this type of radiation to have it in America or Europe, paid for by the NHS.

Your specialist team will give you more information if proton beam therapy is suitable for the type of cancer you have. You can also find out more about proton beam therapy on our website (see page 138).

Planning your radiotherapy

Before you start your treatment, it needs to be planned. This is to make sure the radiotherapy is aimed precisely at the cancer. This also means it causes the least possible damage to the surrounding tissue. Radiotherapy is planned by your clinical oncologist and the radiotherapy team. Planning is important and may take a few visits.

Radiotherapy masks and moulds

If the sarcoma is in a limb or the head and neck area, you may need to have a radiotherapy mask or mould made. This helps keep your head or limb still during radiotherapy treatment sessions. It is made in the mould room on your first visit to the radiotherapy department. Your doctor or specialist nurse will tell you more about moulds if you need one.

Having a mask fitted

We have more information on our website (see page 138).

You do not usually need a mask or mould if you are having radiotherapy to the chest, tummy area (abdomen) or pelvis.

You will be supported with shaped pillows to help keep you still during treatment.

Planning scans

As part of the planning, you will have a CT scan 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. 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 is fed 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 draw the marks on your skin. These marks must stay throughout your treatment, but they can be washed off when your course of treatment finishes.

Often, very small permanent markings are made on the skin (tattoos). They will only be done with your permission. It is a little uncomfortable while the tattoo is being made.

Treatment sessions

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

The treatments are usually given 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 treatment 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 beginning of each session of radiotherapy, the radiographer will explain what to expect. They will position you carefully on the treatment couch as you were during the planning session. When you are in the correct position, the radiographers will leave the room and you will be given your treatment. Radiotherapy is not painful, but you will have to lie still for a few minutes during the treatment.

The radiographers will be able to see and hear you during your treatment.

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 is finished.

Your doctor, nurse or radiographer will discuss this with you, so you know what to expect. Let them know about any side effects you have during or after treatment. There are often things that can be done to help.

Hair loss

You may lose hair from the area being treated by radiotherapy. Treatment for soft tissue sarcomas will not make all the hair on your head fall out. The hair may grow back after the treatment has ended, but the hair loss is often permanent.

We have more information in our booklet **Coping with hair loss** (see page 138).

Skin care

You may find your skin in the treatment area becomes red or darkens. It may also feel sore or itchy. Sometimes the skin gets very sore, and 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. During treatment, you may need to rest more than usual, especially if you have to travel a long way for treatment each day. But it is good to do gentle exercise, such as walking, when you feel able to. This can help boost energy and improve your general well-being.

When your treatment has finished, slowly increase your activity and try to balance rest periods with some physical activity. This will help you build up your energy levels.

Find out more in our booklets **Coping with fatigue** and **Physical activity and cancer treatment** (see page 138).

Feeling sick (nausea)

Some people find their treatment makes them feel sick (nausea) and sometimes be sick (vomit). This is most common when the treatment area is near the tummy area and pelvis. If you have nausea and vomiting, this can usually be effectively treated with anti-sickness drugs (anti-emetics). Your doctor can prescribe these for you.

If you do not feel like eating, you can replace meals with nutritious, high-calorie drinks. These are available from most chemists and can be prescribed by your GP. It is important to keep drinking water, so you do not become dehydrated. It can help to sip drinks slowly if you feel sick. It is important to eat and drink well during treatment to help you cope with and recover from the radiotherapy.

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 surgery or radiotherapy. This means lymph fluid, which circulates around the lymphatic system, cannot pass along the vessels. It builds up, which causes swelling. If lymphoedema develops, it cannot be cured, but it can often be treated and managed.

To help prevent lymphoedema, you should try to avoid getting any infection or inflammation in the area that has been treated with radiotherapy. You should also:

- avoid getting cuts or grazes in the area
- use a moisturiser if your skin gets dry
- not have injections or blood taken from the area
- use high-factor sun protection on the area.

We have more information in our booklet **Understanding lymphoedema** (see page 138).

Stiff joints

Radiotherapy to a joint, such as the knee or elbow, may cause it to become stiff. 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 a fracture in any bones in the treatment area. This is rare and 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 a number of conditions, but it is very important to get it checked.

Second cancer

A small number of people will develop a second cancer because of the radiotherapy treatment they have had. But the chance of a second cancer developing is so small that the risks of having radiotherapy are much smaller than the benefits. You can talk to your cancer specialist if you are worried about your risk of developing a second cancer.

Having chemotherapy

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. It may be given to treat soft tissue sarcomas.
It can be given:

- before surgery (**neo-adjuvant treatment**), to shrink the tumour and make it easier to remove
- after surgery (**adjuvant treatment**), to reduce the risk of the cancer coming back
- to help relieve symptoms and control a sarcoma that cannot be completely removed, or has spread to other parts of the body – this is called **palliative treatment** and may help improve quality of life.

Chemotherapy may not be an effective treatment for some types of soft tissue sarcoma. Your doctor can tell you whether chemotherapy is used to treat your type of soft tissue sarcoma.

How chemotherapy is given

Chemotherapy drugs used to treat soft tissue sarcomas are usually given by injection into a vein (intravenously). They are also sometimes given as tablets.

The most commonly used drugs are:

- doxorubicin
- ifosfamide.

Other drugs that may be used include:

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

We have more information about chemotherapy drugs and combinations on our website (see page 138).

Some of these drugs can be given on their own, but you will usually have a combination of two or more. A targeted therapy drug may also be given at the same time.

Chemotherapy is given as a session (cycle) of treatment.
You may have chemotherapy as an outpatient or you may need to go into hospital for a few days. Each treatment is followed by a rest period of a few weeks to allow your body to recover from any side effects. 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

Chemotherapy can sometimes be given directly into an arm or leg. It can help control cancer that cannot be removed with surgery or has come back in one area. This is also called regional chemotherapy or isolated limb perfusion.

Giving the drugs directly into the affected limb means that very high doses can be given. The affected limb is isolated using a tight band (tourniquet). This stops the chemotherapy drugs going to other areas of the body. This means you are unlikely to get the common side effects of chemotherapy, such as feeling sick. But regional chemotherapy can cause some side effects.

Regional chemotherapy is only done in some specialist centres in the UK. We have more information on our website (see page 138).

Side effects of chemotherapy

Everyone reacts differently to chemotherapy. Some people have very few side effects, and others experience more. The side effects we describe in this information will not affect everyone who is having this treatment.

We have explained the most common side effects, but have not included those that are rare and unlikely to affect you. If you have any side effects that are not listed here, talk to your doctor, chemotherapy nurse or pharmacist.

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.

If you have an infection, it is important to treat it as soon as possible. Contact the hospital straight away on the 24-hour contact number you have 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.

Symptoms of an infection include:

- feeling shivery
- a sore throat
- a cough
- diarrhoea
- needing to pass urine often.

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.

G-CSF (granulocyte-colony stimulating factor) is a type of drug called a growth factor. It encourages the body to make more white blood cells.

Your doctor may give you G-CSF:

- if the number of white blood cells is very low
- to stop the number of white blood cells getting low.

You have it as a small injection under the skin.

Bruising and bleeding

Chemotherapy can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. Tell your doctor if you have any bruising or bleeding that you cannot explain. This includes:

- nosebleeds
- bleeding gums
- tiny red or purple spots on the skin that may look like a rash.

Some people may need a drip to give them extra platelets. This is called a platelet transfusion.

Anaemia (low number of red blood cells)

If chemotherapy reduces the number of red blood cells in your blood, you may become very tired and feel you have no energy. You may also become breathless and feel dizzy and light-headed. These symptoms happen because the red blood cells contain haemoglobin, which carries oxygen around the body.

If your haemoglobin is low, you may be offered a blood transfusion. This will make you feel more energetic and ease any breathlessness.

We have more information about platelet and blood transfusions on our website (see page 138).

Feeling sick (nausea)

You may feel sick in the first few days after this treatment. Your doctor will give you anti-sickness drugs to help prevent or control sickness. 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 and eat small amounts often. If you continue to feel sick, or if you vomit more than once in 24 hours, contact the hospital as soon as possible. They will give you advice and may change the anti-sickness drug to one that works better for you.

Sore mouth

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

If your mouth 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.

Changes to your taste

You may get a bitter or metal taste in your mouth. Sucking sugar-free sweets may help with this. Some foods may taste different or have no taste. Try different foods to find out what tastes best to you. Taste changes usually get better after treatment finishes. Your nurse can give you more advice.

Hair loss

Your hair will get thinner or you may lose all the hair from your head. You may also lose your eyelashes, eyebrows or 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. It is important to cover your head to protect your scalp when you are out in the sun.

Hair loss is almost always temporary and your hair will usually grow back after treatment ends.

We have more information in our **Coping with hair loss** booklet (see page 138).

Feeling tired

Feeling tired is a common side effect. 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 **Coping with fatigue** booklet (see page 138).

Fertility

Your ability to get pregnant or make someone pregnant is likely to be affected by having chemotherapy. It is important to discuss fertility with your doctor before starting treatment. It may be possible for men to store sperm and women to store eggs or embryos for use in the future. For some women, chemotherapy treatment causes an early menopause, and they may have symptoms such as hot flushes and sweats. In many cases, HRT (hormone replacement therapy) can be given to replace the hormones that are no longer being produced. Women with gynaecological sarcomas may not be able to have HRT, because the cancer may be sensitive to hormones.

You may find it helpful to talk 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**.

We have more information in our **Cancer treatment and fertility - information for men** and **Cancer treatment and fertility - information for women** booklets (see page 138).

Contraception

You should not get pregnant or make someone pregnant while having chemotherapy. This is because it may harm the developing baby. It is important to use effective contraception during your treatment and for at least a few months afterwards. You can discuss this with your doctor or nurse.

It is not known whether chemotherapy drugs can get into in semen or vaginal fluids. To protect your partner, it is safest to either avoid sex or use a barrier form of contraception for about 48 hours after chemotherapy.

Targeted therapies

Targeted therapies interfere with the way that cancer cells grow. They are sometimes called biological therapies. They include **cancer growth inhibitors** and **monoclonal antibodies**.

Targeted therapies are often given as part of research trials and are sometimes used to treat soft tissue sarcomas (see pages 102 to 103). We have more information on the following targeted therapy drugs on our website (see page 138).

Imatinib (Glivec®)

Imatinib is a type of treatment called a tyrosine kinase inhibitor (TKI). It may be used to treat GISTs, 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.

Imatinib is taken once a day as tablets. It can cause side effects including:

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

Imatinib can sometimes control GISTs for several years.

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 and 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.

Sunitinib is taken as tablets. Possible side effects include:

- tiredness (fatigue)
- high blood pressure
- diarrhoea
- sore hands and feet
- a sore mouth
- taste changes
- loss of appetite.

Regorafenib (Stivarga®)

This is a newer TKI. It may sometimes be used after imatinib and sunitinib to treat an advanced GIST that cannot be removed with surgery. Regorafenib may shrink the tumour or stop it growing for a time. Regorafenib is taken as tablets that are swallowed whole with a glass of water, after a light meal.

Possible side effects include:

- an increased risk of infection
- loss of appetite
- diarrhoea
- feeling and being sick
- a rash
- sore hands and feet
- hoarse voice
- high blood pressure.

Pazopanib (Votrient®)

Pazopanib is another TKI. It may be used to treat some types of advanced soft tissue sarcoma. 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
- hair colour changes.

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.

Olaratumab (Lartruvo®)

Olaratumab is a type of targeted therapy called a monoclonal antibody. It works by targeting a specific protein on the surface of the cells called PDGFR-alpha. By blocking this protein, olaratumab can cause some tumours to shrink or stop growing for a time.

It may be used to treat advanced soft tissue sarcoma that cannot be treated with surgery or radiotherapy. Olaratumab is given in combination with the chemotherapy drug doxorubicin. It is given by drip into a vein (intravenously).

Possible side effects include:

- an allergic reaction
- feeling or being sick
- tiredness (fatigue)
- diarrhoea
- loss of appetite
- muscle or joint pain.

We have more information in our **Coping with the side effects of treatment** booklet (see page 138).

Research–clinical trials

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

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

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

Taking part in clinical trial

You may be asked to take part in a cancer research trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and develop new treatments. You will be carefully monitored during and after the study.

Usually, several hospitals around the country take part in these trials. It is important to bear in mind that some treatments that look promising at first are often later found not to be as good as existing treatments or to have side effects that outweigh the benefits.

If you decide not to take part in a trial, your decision will be respected and you do not have to give a reason. However, it can help to let the staff know your concerns so that they can give you the best advice. There will be no change in the way that you are treated by the hospital staff, and you will be offered the standard treatment for your situation.

Clinical trials are described in more detail in our booklet **Understanding cancer research trials (clinical trials)** – see page 138.

Blood and tumour samples

Blood and tumour samples may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you take part in a trial you may also give other samples, which may be frozen and stored for future use when new research techniques become available. Your name will be removed from the samples so you can't be identified.

The research may be carried out at the hospital where you are treated, or at another one. This type of research takes a long time, and results may not be available for many years. The samples will be used to increase knowledge about the causes of cancer and its treatment, which will hopefully improve the outlook for future patients.

> ‘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, diagnosed with a soft tissue sarcoma

AFTER YOUR TREATMENT

Follow-up

Most people recover well after treatment for a soft tissue sarcoma. Some people take longer and need extra help. Before you go home, the hospital staff will talk to you about your situation. If you are worried about going home, talk to the hospital staff in advance. They can arrange any help and support you might need.

After your treatment finishes, you will have regular check-ups with your cancer doctor or specialist nurse. They will tell you how often and for how long you will need to have these. It will depend on the type of treatment you had and the risk of the cancer back.

You may have regular tests, including chest x-rays, to check for any signs of the cancer coming back.

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. You can find out more in our **Worrying about cancer coming back** leaflet (see page 138). Or you can speak to our cancer support specialists on **0808 808 00 00**. Some other organisations also offer support to people affected by soft tissue sarcomas. This includes Sarcoma UK, which offers support and information to anyone affected by sarcoma (see page 143 for details). You can talk to its support line nurses on **0808 801 0401** or email **supportline@sarcoma.org.uk**

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.

This can be especially helpful for other people with a soft tissue sarcoma who may be about to start their treatment. Just hearing about how you have coped, what side effects you had and how you managed them is very helpful to someone in a similar situation.

You can share your story and talk with others who have been affected by soft tissue sarcoma on our Online Community at **macmillan.org.uk/community**

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 for you to have an operation to remove the part of the lung that is affected.

If the cancer comes back elsewhere, your doctor will talk to you about your different treatment options. The most common treatment for people in this situation is chemotherapy (see pages 89 to 96).

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 or dealing with some difficult emotions (see pages 116 to 119). 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. If you have health problems, 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

Find out more in our **Giving up smoking** booklet (see page 138).

Drink less alcohol

Current guidelines recommend that both men and women 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 (five portions a day), and 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.

Find out more in our **Healthy eating and cancer** booklet (see page 138).

Keep to a healthy weight

Keeping to a healthy weight reduces the risk of a second cancer, 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. You can find out more in our **Managing weight gain after cancer treatment** booklet (see page 138).

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.

Find out more about how to keep active in our **Move more** guide (see page 138).

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.

> ‘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 a soft tissue sarcoma

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'll have good and bad days, but if you're overwhelmed by these feelings, let your doctor or nurse know. It may be that you have depression, and this is treatable so 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've dreamed about or taking up 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 more healthy diet, by getting fitter or by finding a relaxing complementary therapy.

Understanding about 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 in our **Cancer and complementary therapies** booklet (see page 138).

Who can help

Many people are available to help you and your family.

District nurses work closely with GPs and make regular visits to patients and their families at home if needed.

The hospital social worker can give you information about social services and benefits you may be able to claim, such as meals on wheels, a home helper or hospital fares. The social worker may also be able to arrange childcare for you during and after treatment.

In many areas of the country, there are also specialist nurses called palliative care nurses. They are experienced in assessing and treating symptoms of advanced cancer. Palliative care nurses are sometimes known as Macmillan nurses. However, many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you're at a clinic or in hospital.

Marie Curie nurses help care for people approaching the end of their lives in their own homes. Your GP or hospital specialist nurse can usually arrange a visit by a palliative care or Marie Curie nurse.

There's also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families.

Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.

Your feelings

It's common to feel overwhelmed by different feelings when you're told that you have cancer. We talk about some of these here. Partners, family and friends may also have some of the same feelings.

You might have different reactions to the ones we describe here. There is no right or wrong way to feel. You'll cope with things in your own way. Talking to people close to you or other people affected by cancer can often help.

Shock and disbelief

You may find it hard to believe it when your doctor tells you that you have cancer. It's common to feel shocked and numb. You may not be able to take in much information and find that you keep asking the same questions again and again. At first, you might find it hard to talk to family and friends about the cancer. This usually gets easier as the shock wears off and it becomes more real to you. You may find you can't think or talk about anything but the cancer. This is because your mind is trying to process what you're going through.

Fear and anxiety

People can be very anxious or frightened about whether treatment will work and what will happen in the future. This uncertainty can be one of the hardest things to cope with. It can help to try to focus on what you can control. You may want to find out more about the cancer, its treatment and how to manage side effects. It can also help to talk about your feelings and to take time to do things that are important to you and that you enjoy.

Doctors often know roughly how many people can benefit from a type of treatment. But they can't be sure what will happen to an individual person. Although they may not be able to answer your questions fully, they can usually talk through any problems with you and give you some guidance.

Avoidance

Some people cope by not wanting to know very much about the cancer and by not talking about it. If you feel like this, let your family and friends know that you don't want to talk about it right now. You can also tell your doctor if there are things you don't want to know or talk about yet.

Occasionally, this avoidance can be extreme. Some people may not believe that they have cancer. This is sometimes called being in denial. It may stop them making decisions about treatment. If this happens, it's very important for them to get help from their doctor.

Sometimes, avoidance is the other way around. Family and friends may seem to avoid you and the fact that you have cancer. They may not want to talk about it or they might change the subject. This is usually because they are also finding the cancer difficult to cope with, and they may need support too. Try to let them know how this makes you feel and that talking openly with them about your illness will help you.

Anger

You may feel angry about your illness and sometimes resent other people for being well. These are normal reactions, especially when you feel frightened, stressed, out of control or unwell. You may get angry with the people close to you. Let them know that you are angry at your illness and not at them. Finding ways to help you relax and reduce stress can help with anger. This can include talking about or writing down how you feel, gentle exercise, breathing or relaxation therapy, yoga or meditation.

Guilt and blame

Some people feel guilty or blame themselves or others for the cancer. You may try to find reasons for why it has happened to you. Most of the time, it's impossible to know exactly what has caused a person's cancer. Over time, several different factors may act together to cause a cancer. Doctors don't fully understand all of these factors yet. Instead, try to focus on looking after yourself and getting the help and support you need.

Feeling alone

Some people feel alone because they don't have enough support. Family and friends may live far away, have other commitments or feel uncomfortable because of their own fears about cancer. Try to let your family and friends know how you feel and how they could support you more.

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find out about local support groups – visit **macmillan.org.uk/supportgroups** You can also talk to other people going through the same thing on our Online Community at **macmillan.org.uk/community**

It's normal to have times when you want to be left alone to sort out your feelings. But if you find you're avoiding people a lot of the time, then try to talk to your doctor or nurse.

If you need more help

These feelings can be very difficult to cope with and sometimes people need more help. This happens to lots of people and doesn't mean you're not coping.

If you feel anxious, panicky or sad a lot of the time, or think you may be depressed, talk to your doctor or nurse. They can refer you to a doctor or counsellor who can help. They may also prescribe medicine to help with anxiety or an antidepressant drug.

Our booklet **How are you feeling? The emotional effects of cancer** discusses the feelings you may have in more detail, and has suggestions for coping with them (see page 138).

YOUR RELATIONSHIPS

Relationships

Your experience of cancer may have improved and strengthened your relationships with people close to you. You may feel that you would not have been able to cope so well without the support you have had from family and friends.

However, cancer is stressful and this sometimes has an effect on your relationships. Problems usually improve over time, especially if you can talk openly with each other. We have listed some of the issues that can arise in relationships and some ways of coping with these.

Family and friends

You may sometimes feel that your family and friends do not understand if you are not feeling positive about getting on with things. You may feel they do not realise how much the effects of treatment are affecting your life. Talking openly about how you are feeling will help them to understand you better and give you the support you need.

We have more information in our **Talking about cancer** booklet that you might find helpful (see page 138).

Talking to children

Deciding what to tell your children or grandchildren about your cancer is difficult. An open, honest approach is usually best. Even very young children can sense when something is wrong, and their fears can sometimes be worse than the reality.

How much you tell your children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information, and gradually tell them more to build up a picture of your illness.

Teenagers

Teenagers can have an especially hard time. At a stage when they want more freedom, they may be asked to take on new responsibilities and they may feel over-burdened. It is important that they can go on with their normal lives as much as possible and still get the support they need.

If they find it hard to talk to you, you could encourage them to talk to someone close who can support and listen to them, such as a grandparent, family friend, teacher or counsellor. They may also find it useful to look at the website **riprap.org.uk,** which has been developed especially for teenagers who have a parent with cancer (see page 144).

Your partner

Some couples become closer as a result of sharing the experience of cancer. However, cancer can put a lot of strain on a relationship. Problems sometimes develop, even between close and loving couples who have been together for a long time.

Talking openly about your feelings and listening to each other can help you to understand each other's point of view.

We have more information in our booklets **Cancer, you and your partner**, **Cancer and your sex life - information for men** and **Cancer and your sex life - information for women** that may help (see page 138).

WORK AND FINANCIAL SUPPORT

Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Wales and Scotland or **nidirect.gov.uk** if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by cancer.

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who cannot work because of illness or disability. There are different types of ESA:

- Contribution-based ESA may be available if you have paid enough National Insurance.
- Income-related ESA may be available if your income and savings are low, or if you cannot get contribution-based ESA. Income-related ESA is gradually being replaced by a new benefit called Universal Credit.

Personal Independence Payment

This benefit is for people aged between 16 and 64 who have problems moving around and looking after themselves. You must have had these difficulties for at least 3 months and expect them to last for at least 9 months.

Attendance Allowance

This benefit is for people aged 65 or over who have problems looking after themselves because of an illness or disability. This could mean getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months.

Special rules

If you are terminally ill, and your doctor thinks you may be expected to live for less than 6 months, you can apply for some benefits using a fast-track process called special rules. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

Help for carers

Carer's Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you do not qualify for it, you can apply for Carer's Credit.

Carer's Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

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, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. The average grant is around £400. A grant from Macmillan would not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are looking into buying insurance or making a claim, one of our financial advisers can help. Call **0808 808 00 00**.

We have more information in our booklets **Insurance** and **Travel and cancer** (see page 138). Our Online Community forum **Travel insurance** may also be helpful. Visit **macmillan.org.uk/travelinsurancegroup**

More information

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 one by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice (see page 148).

Our booklet **Help with the cost of cancer** has lots more information (see page 138).

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 early on. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others carry on working, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to take on too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful (see page 138). There is also lots more information at **macmillan.org.uk/work**


11:25 13-SEP-2011
Phonebook Hotdesk

Employment rights

If you have, or have ever had cancer, the law considers you to be disabled. This means you cannot be treated differently (less favourably) than other people at work because of cancer. If you are treated less favourably because of cancer, this is called discrimination.

The law also says your employer has to make reasonable adjustments (changes) to your workplace and their work practices.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 138).

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 leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

Online information

All of our information is also available at **macmillan.org.uk/information-and-support** There you'll also find videos featuring real-life 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'd 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**.

Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email **reviewing@macmillan.org.uk** You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're 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 Monday to Friday, 9am to 8pm. Our cancer support specialists 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.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.
Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.
Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

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's why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, 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**

The Macmillan healthcare team

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.

> 'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'
>
> **Mal**

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

Financial guidance

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

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

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 a financial guide or benefits adviser, or to find out more about Macmillan Grants. 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 work and cancer

Whether you're 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**

My Organiser app

Our free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

Other useful organisations

There are lots of other organisations that can give you information or support.

Sarcoma support organisations

GIST Support Network

Tel 0300 400 0000
Email admin@gistsupportuk.com
www.gistsupportuk.com

A network of patients and carers, providing information and support to anyone affected by a GIST.

Sarcoma UK

Tel 020 7250 8271
Email info@sarcoma.org.uk
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

Cancer Black Care

Tel 020 8961 4151
www.cancerblackcare.org.uk

Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

Cancer Focus Northern Ireland

Helpline 0800 783 3339 (Mon to Fri, 9am to 1pm)
Email nurseline@cancerfocusni.org
www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

Cancer Research UK

Helpline 0808 800 4040
(Mon to Fri, 9am to 5pm)
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
(Mon to Fri, 9am to 5pm)
Email info@cancersupportscotland.org
www.cancersupportscotland.org

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

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 Centres

Tel 0300 123 1801
Email enquiries@maggiescentres.org
www.maggiescentres.org

Has a network of centres in various 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
(Mon to Fri, 9.30am to 5pm)
Email helpline@pennybrohn.org.uk
www.pennybrohn.org.uk

Offers a combination of 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
(Daily, 8am to 8pm)
Email info@tenovuscancercare.org.uk
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.hscni.net

Provides information about health and social care services in Northern Ireland.

Healthtalk

Email info@healthtalk.org
www.healthtalk.org
www.healthtalk.org/young-peoples-experiences (site for young people)

Has information about cancer, and videos and audio clips of people's experiences. Also provides advice on topics such as making decisions about health and treatment.

NHS.UK

www.nhs.uk

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

NHS Direct Wales

www.nhsdirect.wales.nhs.uk

NHS health information site for Wales.

NHS Inform

Helpline 0800 22 44 88
(Mon to Fri, 8am to 10pm, Sat and Sun 9am to 5pm)
www.nhsinform.scot

NHS health information site for Scotland.

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- and illness-related websites.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel 01455 883 300
Email bacp@bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

UK Council for Psychotherapy (UKCP)

Tel 020 7014 9955
Email info@ukcp.org.uk
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

Mind

Helpline 0300 123 3393
(Mon to Fri, 9am to 6pm)
Text 86463
Email info@mind.org.uk
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
Samaritans branches are located across England, Ireland, Scotland and Wales. Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Equipment and advice on living with a disability

British Red Cross
Tel 0344 871 11 11
Textphone 020 7562 2050
Email contactus@redcross.org.uk
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
Email enquiries@disabilityrightsuk.org
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.

Disabled Living Foundation (DLF)
Helpline 0300 999 0004
(Mon to Fri, 10am to 4pm)
Email info@dlf.org.uk
www.dlf.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.

Limbless Association
Helpline 0800 644 0185
Email enquiries@limbless-association.org
www.limbless-association.org
Offers support and information to people who are about to have an amputation, or those already living with limb-loss.

Scope
Helpline 0808 800 3333
(Mon to Fri, 9am to 5pm)
Email helpline@scope.org.uk
www.scope.org.uk
Offers confidential advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.

Financial or legal advice and information

Benefit Enquiry Line Northern Ireland

Tel 0800 022 2450 (Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)
Textphone 0289 031 1092
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland. You can also call the Make the Call helpline to check you are getting all the benefits you are eligible for.

Citizens Advice

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

England

Helpline 03444 111 444
www.citizensadvice.org.uk

Wales

Helpline 03444 77 2020
www.citizensadvice.org.uk/wales

Scotland

Helpline 0808 800 9060
www.citizensadvice.org.uk/scotland

Northern Ireland

Helpline
028 9023 1120
www.citizensadvice.co.uk

Civil Legal Advice

Helpline 0345 345 4345 (Mon to Fri, 9am to 8pm, and Sat, 9am to 12.30pm)
Minicom 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 isn't your first language.

Department for Work and Pensions (DWP)

Personal Independence Payment (PIP)

Helpline 0800 121 4433 (Mon to Fri, 8am to 6pm)
Textphone 0800 121 4493

Carer's Allowance Unit

Tel 0800 731 0297
Textphone 0800 731 0317
(Mon to Fri, 8 am to 6pm
www.gov.uk/browse/benefits

Manages state benefits in England, Scotland and Wales. You can apply for 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.

Money Advice Scotland

Tel 0141 572 0237
Email info@moneyadvicescotland.org.uk
www.moneyadvicescotland.org.uk

Use the website to find qualified financial advisers in Scotland.

National Debtline (England, Wales and Scotland)

Tel 0808 808 4000
(Mon to Fri, 9am to 8pm, and Sat, 9.30am to 1pm)
www.nationaldebtline.org

A national helpline for people with debt problems. The service is free, confidential and independent. Has an online chat service with an expert debt advisor.

NiDirect

www.nidirect.gov.uk

Has information about benefits and public services in Northern Ireland.

Personal Finance Society – 'Find an Adviser' service

www.thepfs.org/yourmoney/find-an-adviser

Use the website to find qualified financial advisers in your area of the UK.

The Money Advice Service

Helpline
0800 138 7777 (English)
0800 138 0555 (Welsh)
(Mon to Fri, 8am to 8pm,
and Sat, 9am to 1pm)
Typetalk
18001 0300 500 5000
Email enquiries@moneyadviceservice.org.uk
www.moneyadviceservice.org.uk
Runs a free financial health check service and gives advice about all types of financial matters across the UK. Has an online chat service for instant money advice.

Unbiased.co.uk

Helpline 0800 023 6868
Email contact@unbiased.co.uk
www.unbiased.co.uk
You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

Support for carers

Carers Trust

Tel 0300 772 9600
(Mon to Fri, 9am to 5pm)
Email info@carers.org
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
(Mon and Tue, 10am to 4pm)
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 support groups for carers in their area.

Support for young people

CLIC Sargent

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

Teenage Cancer Trust

Tel 0207 612 0370
(Mon to Fri, 9am to 5.30pm)
Email hello@teenagecancertrust.org
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.

Youth Access

Tel 020 8772 9900
(Mon to Fri, 9.30am to 1pm, then 2pm to 5.30pm)
Email admin@Youthaccess.org.uk
www.youthaccess.org.uk
A UK-wide organisation providing counselling and information for young people. Find your local service by visiting **youthaccess.org.uk/find-your-local-service**

Support for older people

Age UK

Helpline 0800 055 6112
(Daily, 8am to 7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

Tel 0345 330 3030
(Mon to Fri, 10am to 10pm, and Sat 10am to 6pm)
Email helpline@lgbt.foundation
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.

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, Medical Oncologist; Professor Timothy Briggs, Sarcoma Surgeon; Ann Buchan, Sarcoma Clinical Nurse Specialist; Lynsey Green Clinical Specialist Sarcoma Physiotherapist; Professor Ian Judson, Professor of Cancer Pharmacology; Dr Michael Leahy, Consultant Medical Oncologist; Dr Jenny Sherriff, Consultant Clinical Oncologist; Mr Ian M Smith, Consultant Plastic Surgeon; and Joyce Warren, Radiographer.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

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

Sources

We have listed a sample of the sources used in the booklet below. If you would like further information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

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Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're 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're there 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

Share your cancer experience

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

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.

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?

Raise money

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

Give money

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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 family members and friends.

The booklet explains the signs and symptoms of soft tissue sarcoma and how it is diagnosed and treated. It also has information about emotional, practical and financial issues.

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm, or visit **macmillan.org.uk**

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