



# Understanding sarcoma

## Head and Neck

[sarcoma.org.uk](http://sarcoma.org.uk)



**Sarcoma UK**  
The bone & soft tissue  
cancer charity

# About this booklet

This booklet is aimed at anyone who has a diagnosis of sarcoma in the head or neck area.

- It explains what head and neck sarcoma is, how it is diagnosed and what treatment options are available to you
- It is your personal guide with space available to keep all your diagnostic information and the details of your hospital appointments
- You can also include the contact details of your doctor, sarcoma clinical nurse specialist or other healthcare professionals

You may find it useful to share the information in this booklet with your family members, partner, or friends. If you have questions about anything you read in this booklet, please contact Sarcoma UK.

**The information provided in this booklet is only for adult patients. Due to the different treatment procedures and services for children diagnosed with sarcoma, it should not be used by parents as a guide to their child's care.**

**Treatment may vary depending on which area of the UK you live in. Please ask your doctor or sarcoma Clinical Nurse Specialist (CNS) about the treatment options available in your area.**

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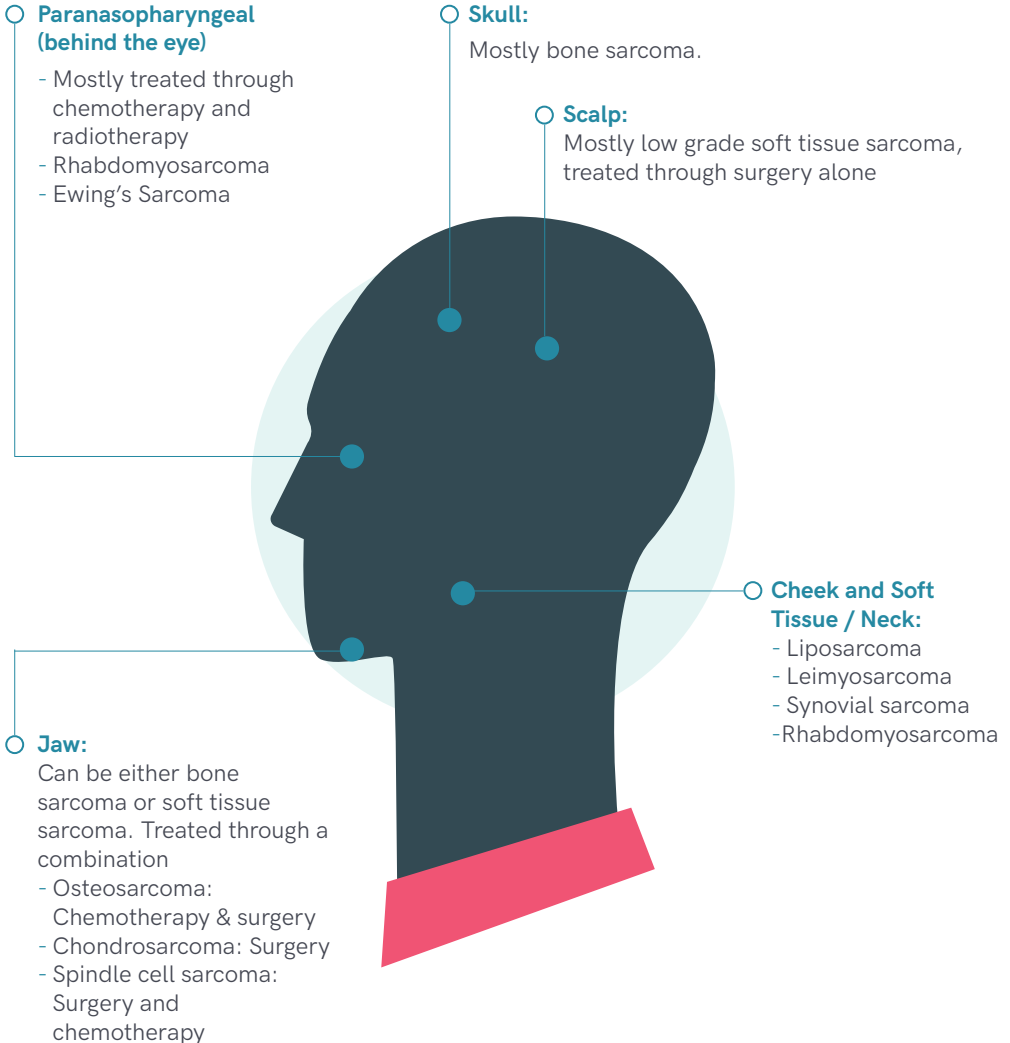
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# What is head and neck sarcoma?

Sarcoma is an uncommon cancer that can develop in the body's connective tissues, muscle, bone, cartilage, tendons, blood vessels or the fatty and fibrous tissues.

Head and neck sarcomas are a group of tumours which can develop anywhere in the head and neck area. They can be a range of different subtypes and can develop in the bone or soft tissue.

# Sites of the head and neck sarcoma



# Signs and symptoms



What subtype of sarcoma do I have?

The symptoms of head and neck sarcoma can vary depending on the location of the tumour. You might experience:

- A blocked nose
- Facial pain
- Swelling
- Loose teeth
- A loss of sensation in a particular area
- Weight loss
- A lump or swelling

You might experience more than one of these symptoms at different times throughout your treatment. If you are concerned, you can speak to your treatment team or your Clinical Nurse Specialist.

# How is head and neck sarcoma diagnosed?

A diagnosis of head and neck sarcoma may start with a visit to your GP or dentist who will then refer you to a specialist doctor.

A doctor can use several tests to find out whether your symptoms are due to a sarcoma. These tests might include:

- **Physical examination:** A doctor may look at or feel any visible lump. This will depend on the location and type of your suspected sarcoma.
- **A scan:** A doctor might take pictures of the inside of your body using a specialised scan. This might be an ultrasound, a CT scan, PET scan or an MRI.
- **An ultrasound guided core needle biopsy:** A doctor will take a tissue sample of the tumour or lump, using an ultrasound to guide a needle to the right place, under local anaesthesia.
- **An open biopsy:** When a larger piece of tissue needs to be taken for examination, a doctor will take a tissue sample of the tumour under local or general anaesthesia.

Your diagnosis will be made after a pathologist with experience of sarcoma has examined your tissue sample.

*"A doctor can use several tests to find out whether your symptoms are due to a sarcoma."*

# What tests or scans might I have?



What sort of tests will I have?

How long do I have to wait for these tests to be carried out?

When will I get my test results?

How will I get my results?

The tests and scans used to diagnose and assess your sarcoma can vary depending on where the tumour is. The most common scans for head and neck sarcoma are:

- **Ultrasound:** An ultrasound is a scan that uses sound waves to create images from within the body. A scanning microphone is moved over the part of the body that is being scanned. Gel is placed on the skin beforehand to help the scan work better. In the majority of cases your ultrasound will be carried out by a specialist head and neck radiologist.
- **MRI:** Magnetic Resonance Imaging (MRI) uses magnets to create an image of the tissues of the body.
- **CT Scan:** A Computer Tomography (CT) scan takes a number of x-rays to make a 3D image of an affected area. If you are diagnosed with head and neck sarcoma, you might have a CT scan of your head and neck, and a separate CT scan of your chest to check if your cancer has spread to other areas. If your cancer spreads to another part of the body, this is called a metastasis.
- **A PET-CT scan:** A Positron Emission Tomography (PET) scan is used to produce three dimensional images of the inside of the body. It is useful for determining how far a cancer has spread. This is combined with a CT scan to produce more detailed images.



- **Nasendoscopy:** A procedure which allows a doctor to see the back of your throat and voice box

Your oncologist should explain what scans you need and why you need them. It is likely that you'll have more than one scan, but if there is anything you are concerned about or don't understand, you can ask any questions at any time.

# Understanding your diagnosis

Identifying the stage and grade of a tumour means your oncologist is able to advise on the best course of treatment for you. Staging and grading describes the cancer in a common language, which is useful when your case is discussed with other doctors or healthcare professionals.

The stage of a cancer is measured by how much it has grown or spread, which can be seen on the results of your tests and scans. The results from a biopsy can tell what grade the cancer is.

## Grading

- Low-grade means the cancer cells are slow-growing, look quite similar to normal cells, are less aggressive and are less likely to spread
- Intermediate-grade means the cancer cells are growing slightly faster and look more abnormal
- High-grade means the cancer cells are faster growing, look very abnormal, are more aggressive and have more potential to spread to other areas of the body

*"If there is anything you are concerned about or don't understand, you can ask any questions at any time."*



Has my case been seen by a sarcoma MDT?

Who is my key worker/ sarcoma clinical nurse specialist (CNS)?

Who are the members of my MDT?

Who do I contact in an emergency or out of hours?

## Staging

Most sarcomas are staged by looking at:

- The size and grade of the tumour
- Whether a tumour is deep in the body or close to the surface
- Whether the tumour has spread to another part of the body

Bone and soft tissue sarcomas are staged slightly differently. Your doctor will explain this to you and will be able to answer any questions you might have.

# Who will treat me?

In England and Wales, the National Institute for Health and Care Excellence (NICE) recommends that anyone with a sarcoma should be referred to a sarcoma multidisciplinary team (MDT) to have their care plan discussed and confirmed.

In Northern Ireland, bone and soft tissue sarcomas are diagnosed and treated across a number of hospitals across Belfast.

In Scotland, bone and soft tissue sarcomas are treated at regional centres across the country. These are based in

- Glasgow
- Inverness
- Aberdeen
- Dundee
- Edinburgh

Your multidisciplinary team (MDT) will be made up of a wide range of health care professionals,

including your sarcoma clinical nurse specialist, your surgeon, and other healthcare professionals who are involved in your care.

Because head and neck sarcomas are complex, you might also be referred to a head and neck multidisciplinary team, who specialise in treating the part of the body that is affected.

There should be clear communication between your head and neck MDT and your sarcoma MDT to ensure that there is specialist input into your treatment plan.

## What treatment is available?

Your treatment for head and neck sarcoma is highly individualised. It will depend on the size and location of your tumour, your physical health and the advice of your doctor or medical team.

Your MDT will discuss your case and your oncologist or nurse will talk you through your treatment options. It is important that you feel included in any decisions and feel able to ask any questions you might have.

### Surgery

Surgery is the main treatment option for most head and neck sarcomas. Your surgeon will remove the tumour and will aim to take out an area of healthy tissue around it. This is known as taking a margin.

Head and neck sarcomas can sometimes touch or press on surrounding areas in the head. In these cases, your surgeon will aim to remove the tumour along with the tissue next to it. This is known as

*"Because head and neck sarcomas are complex, you might also be referred to a head and neck multidisciplinary team."*

*"Surgery is the main treatment option for most head and neck sarcomas"*



What are my treatment options?

What is the likely outcome of my recommended treatment?

Can I get a second opinion? If so, how can I get one?

removing a tumour 'en bloc'. Sometimes this will mean taking out blood vessels, lymph nodes, soft tissue and bone.

Surgery for head and neck sarcoma can affect your appearance and leave you with difficulties in speech and swallowing. You will be given specialist advice and support to explain how this will affect you and there is more information on pages 12-15 of this booklet.

The treatment you receive should take into account your individual situation, and your doctor or clinical nurse specialist should talk you through all possible treatment options. You should also have the opportunity to ask any questions you might have.

In some cases, it might not be possible to remove the tumour completely. In these cases, it is unlikely that surgery will be recommended.

#### Chemotherapy:

Chemotherapy uses anti-cancer drugs to destroy cancer cells.

Using chemotherapy as a treatment for head and neck sarcoma depends on the subtype of the tumour, as different sarcoma subtypes respond to chemotherapy in different ways.

For some subtypes of sarcoma, chemotherapy is used to try and shrink a large tumour or stop it spreading, so that it is safe to be operated on. In other cases, you might need a combination of chemotherapy, radiotherapy or surgery. Your medical team will be able to talk you through the available options.

It might also be used to stop a sarcoma spreading further. In other cases, you might need a combination of chemotherapy, radiotherapy or surgery. Your medical team will be able to talk you through the available options.

## Radiotherapy:

This treatment uses high energy radiation beams to destroy cancer cells. It is used to treat soft tissue sarcomas of the head and neck.

In some cases, radiotherapy can be used before surgery to shrink the tumour, allowing doctors to operate and remove it more easily.

Radiotherapy can also be used after surgery to kill any local cancer cells. When radiotherapy is used with the aim of curing a tumour, this is called radical radiotherapy.

Before beginning radiotherapy, you might have a number of tests. These can include:

- A dental assessment
- A hearing assessment
- An appointment with a dietician
- You might be assessed for a feeding tube, which can be used to ensure you have nutrition, water and medication. More information can be found in the 'What support is available' section of this booklet.

Before beginning radiotherapy, you will be fitted for a plastic shell or mask. This helps to position you, so that the radiotherapy can be accurately delivered to the same site every day. Depending on where the radiation is being delivered, it might be possible for eye holes to be cut in your mask. Your treatment team will discuss this with you and you can ask any questions and discuss any fears you might have.

You can find more information on how to prepare for radiotherapy in Sarcoma UK's Rehabilitation and Life after Treatment booklet. This can be downloaded from the Sarcoma UK website or ordered online.

*"Before beginning radiotherapy, you might have a number of tests."*

What are the side effects of the treatments recommended to me?



*"Proton beam therapy is useful when treating cancers in sensitive areas."*

### Proton Beam Therapy:

Proton beam therapy is a type of radiotherapy. In order to kill cancer cells, it uses small parts of atoms (called protons) rather than high energy x-rays.

Proton beam therapy differs from conventional radiotherapy because the beam of protons stops once it hits the cancerous cells. This means that proton beam therapy causes less damage to the surrounding tissue. As a result, it can reduce some of the side effects of radiotherapy.

Proton beam therapy is useful when treating cancers in sensitive areas, or in areas where it is important to reduce damage to the surrounding tissue. However, proton beam therapy would not be suitable in most cases and would not be recommended for treatment.

## How might my treatment impact my everyday life?

Every form of head and neck sarcoma is treated differently, but there are some common issues which people may face while recovering. The following section contains some practical advice on dealing with these.

**Appearance:** Your treatment or surgery might cause permanent changes to your appearance.

Some surgeries for sarcomas in the head or neck require facial reconstruction. This might mean that you need more than one surgery over a prolonged period of time. This will be discussed with your medical team.

There are a number of charities which focus on providing emotional support for those affected by head and neck cancer and its treatments.

You can find more information on these in the 'What support is available' section of this booklet.

### **Short term side effects:**

#### **Eating and drinking:**

After treatment, some people find it difficult to eat or drink as they usually do. This varies from person to person and can improve over time. In the short term, you might experience:

- **Issues with the muscles of the mouth:** If your surgery has affected the muscles in your mouth, you might struggle to chew and swallow your food, or find it difficult to move your mouth or tongue. You might experience a dry mouth or loss of appetite as a result of this. This usually lessens over time.
- **Sore mouth and throat:** If you have had radiotherapy or chemotherapy, you might find eating or drinking painful. Occasionally, radiotherapy can affect the amount of saliva you produce, which can lead to a dry mouth.

#### **Dry mouth:**

If you are struggling with the symptoms of dry mouth, you might find it useful to:

- Carry a bottle of water with you.
- Do not smoke. If you need advice on stopping smoking, you can find it here: [www.nhs.uk](http://www.nhs.uk)
- Limit your intake of alcohol or caffeine where possible.

*"Some surgeries for sarcomas in the head or neck require facial reconstruction."*

*"Do not smoke. If you need advice on stopping smoking, you can find it here [www.nhs.uk](http://www.nhs.uk)"*

*"You should consult your speech and language therapist, CNS or oncologist before following this advice."*

*"Difficulty swallowing after radiotherapy can be a longer term issue and you will be given advice on how to deal with it."*

You might find it helpful to:

- **Drink lukewarm or tepid water rather than cold.** This is easier to swallow and can occasionally help relieve the symptoms of dry mouth.
- **Blend your food.** This can help you to swallow more easily and can be less painful to eat. You might also find it helpful to use sauces to make foods easier to eat.
- **Practise good mouth care.** This could involve brushing your teeth regularly with prescription toothpaste, or using a prescribed mouthwash. Certain mouthwashes contain local anaesthetic, which can help relieve pain. If you have a Speech and Language therapist, they will be able to provide more specific advice on this.

You should consult your speech and language therapist, CNS or oncologist before following this advice.

Macmillan provide a comprehensive guide with practical steps on how to relieve dry mouth. Their information can be found on the Macmillan website under the Information and Support section (Information and Support – Head and Neck Cancers – Coping – Side Effects and Symptoms).

#### Swallowing:

Difficulty swallowing is called dysphagia. Treatment for a head and neck sarcoma can sometimes affect your ability to swallow. This might happen as a result of where your sarcoma is, as a consequence of surgery or because you have had chemotherapy or radiotherapy to your head and neck.

- You might have difficulty swallowing immediately post-surgery. This is usually short term and can be managed with advice from your clinical nurse specialist or treatment team.
- Difficulty swallowing after radiotherapy can be a



longer term issue and you will be given advice on how to deal with it.

If you are experiencing difficulty swallowing, you will be supported by a member of the Speech and Language Therapy team, and by a dietician. They will make an assessment of whether you have any nutritional needs as a result of your dysphagia. They will also be able to give you practical dietary advice.

#### Speech:

Occasionally, your speech might be affected by your treatment or surgery. This will depend on what treatment you have had.

To begin with, you might find it difficult to speak clearly after your treatment. You might find that your voice sounds more strained or hoarse than you are used to, or that you have trouble moving your tongue or lips. This is usually short term, as your body adjusts to your treatment and you learn new ways of communicating.

#### Speech and tracheostomy:

Sometimes surgery for a head and neck sarcoma might require you to have a tracheostomy. Your surgeon might recommend this if they think that surgery to your mouth or throat could cause swelling or make it difficult for you to breathe.

A tracheostomy involves making an opening in your windpipe, which is held open by a small tube (called a tracheostomy tube). Rather than breathing through your nose and mouth, air will flow in and out of the tracheostomy tube to help you breathe.

Depending on the type of treatment you have, you might have the tracheostomy tube as a short or long term method of managing your breathing.

You will not be able to speak while you have a tracheostomy tube. However, you will find other ways to communicate, which might include:

*"During or after your treatment, you might feel more tired or fatigued than usual."*

*"If you have had radiotherapy, your skin might change around the site where you've been treated."*

- Writing notes, using a notepad or computer/tablet/phone. This can help you to communicate in the short term
- Using non-verbal communications such as gestures or signs

Your Clinical Nurse Specialist will be able to provide more specific support on this.

### Energy:

During or after your treatment, you might feel more tired or fatigued than usual. This can be made worse by a loss of appetite or lack of food. You might find the following steps helpful to maintain your energy.

Activities which you might not have considered before treatment - such as making breakfast or taking a shower - can seem daunting or exhausting for many people. This is normal both during and for some time after treatment.

- Many people find that small adjustments like taking rest breaks help to manage these changes. For example, you might have breakfast and a shower and then plan a short rest before your next activity.
- It can be helpful to do light exercise to combat fatigue. You should check this with your medical team before starting.

### Changes to skin:

If you have had radiotherapy, your skin might change around the site where you've been treated. These side effects usually develop after three to four weeks of treatment. They do not develop for everyone, and they can be managed with advice from your Clinical Nurse Specialist or treatment team.

- Your skin might feel firmer, or become tighter or dryer than you are used to. Some people find it helpful to use mild soaps, cleansing lotions or creams rather than foaming washes, as these can dry the skin.

However, this should be discussed with your radiotherapist because some cosmetics might irritate the skin and interfere with treatment.

- Your skin might change colour and become darker during or after radiotherapy. You can ask your CNS for advice on this, and they might refer you to a skin specialist or dermatologist.

*"Some people find it helpful to use mild soaps, cleansing lotions or creams rather than foaming washes, as these can dry the skin."*

# What if I'm in pain?

*"You can speak to your treatment team or CNS about options for pain management."*

There are lots of treatments available to help you manage pain before, during or after your treatment. Your treatment team will be able to advise you on these, but as a guide, they might involve:

- A local anaesthetic specific to the area that is in pain. For example, there are prescription mouthwashes which contain localised anaesthetic, which can help with pain in your mouth.
- You can speak to your treatment team or CNS about options for pain management. They might refer you for complimentary therapies such as acupuncture.
- The NHS provide information on ongoing pain management, and list a range of support groups which you might find helpful. More information can be found on the NHS website at [www.nhs.uk/live-well](http://www.nhs.uk/live-well)

# What happens after I have had my treatment?

Once you have recovered from surgery, your medical team will suggest you have routine follow up appointments.

Initially, these might be every few months or quarterly, but your treatment team will discuss this with you in more detail.

You will be given a point of contact who you can speak to between appointments if you have any concerns.

- The aim of the follow up appointment is to check for signs that your sarcoma has come back, or that it has spread to another part of the body.

The follow up appointment will consist of some basic tests. These usually involve blood tests and a clinical examination. You might also need a chest x-ray or a CT or MRI scan.

It is usual to feel some anxiety in the time before your follow up, and this might continue throughout the visit. This is sometimes referred to as 'scan anxiety' or 'scanxiety', and is a very normal feeling. However, there are steps you can take to ease your anxiety and prepare for your appointment.

*"The aim of the follow up appointment is to check for signs that your sarcoma has come back, or that it has spread to another part of the body."*

# Preparing for an appointment



How often will I have my follow-up appointments?

Where will I have my follow-up appointments?

*"Write a list of questions/concerns that you want to discuss."*

- A follow up appointment is a chance for you to raise any issues or concerns, and to talk these over with your medical team. The appointment will be focused on you, and concerned with making you as comfortable and reassured as possible.
- You might want to take a family member or friend with you to the appointment. They can make notes for you and remind you of the questions you want answers to.
- Write a list of questions/concerns that you want to discuss. Take the list with you, so that you can be reminded throughout the appointment.
- When you are given the results of tests/scans, you might not immediately understand what is being said. This is natural, and the doctor or medical team will understand. You can ask the doctor to repeat what has been said, and to explain any terms which you don't understand.
- Don't forget that the nurses in the clinic are experts and will be able to answer many of your questions.

# Will my cancer come back?

Like any cancer, head and neck sarcoma can reappear in or near the same area after treatment. This is called a local recurrence. It may also spread within the head and neck region. If the sarcoma does come back, it is important to get treated as quickly as possible.

If you are worried about your sarcoma returning, contact your doctor or Clinical Nurse Specialist. They may decide to bring forward the date of your follow up appointment to investigate your concerns.

*What if my cancer spreads to another part of my body?*

A recurrence of sarcoma may be accompanied by cancer in other parts of the body. This is called a metastasis or secondary cancer. Some people are diagnosed with sarcoma because their metastases have been discovered before their primary sarcoma tumour. In sarcoma patients, secondary cancers might appear in the lungs, which is why a chest x-ray is taken at follow up appointments. However, this is less common in cases of head and neck sarcoma.

*How do I cope emotionally/psychologically with my treatment?*

Your treatment will focus on your physical health. However, it is important to recognise the emotional impact that a sarcoma diagnosis can have.

You might feel angry, scared or isolated. It is very common to experience a range of different emotions,



Ask your doctor or sarcoma clinical nurse specialist for more information signs and symptoms to look out for?

*"Like any cancer, head and neck sarcoma can reappear in or near the same area after treatment."*

*"It is really important to understand that there is no right or wrong way to deal with diagnosis."*

and to be unsure how you are feeling or why you are feeling that way.

As sarcoma is a rare form of cancer, you might feel like people don't understand what you are going through, or that you don't have the information you need to deal with your diagnosis. You might be concerned for your family and friends, or worried about the way you are coping.

It is really important to understand that there is no right or wrong way to deal with diagnosis. Everyone is affected differently, and will find their own ways to come to terms with what is happening.

You might find it helpful to speak to a family member or friend about how you are feeling. Equally, you might want to speak to someone outside your family, and might find it helpful to seek professional emotional support. You can find more information in the 'What support is available' section of this booklet.

### How do I cope with long term treatment?

Coping with a diagnosis of head and neck sarcoma can be frightening. The treatment and recovery can be a long process, and you might have to get used to a new idea of what is 'normal' in your everyday life. You might be concerned about the following issues:

- **Repeated surgery:** Some people find that they need repeated surgeries for cosmetic or reconstructive reasons. Depending on the type of treatment you need, there can sometimes be extended waiting periods for these procedures. This can be frustrating and can have an impact on your overall psychological health.
- **Appearance:** After finishing treatment, you might feel upset or frustrated about your appearance. Sometimes you might feel guilty for feeling this way, but it is important to remember that adjusting to a new normality can take time. You



might find it helpful to speak to others who have been in a similar position. You can find more support in the 'What Support is Available' section of this booklet.

- **Day to day life:** Treatment for head and neck sarcoma can affect fundamental parts of your day to day life. It can change things which are sometimes taken for granted, such as your speech or the ability to eat or drink. Although there are ways to cope with these changes, it can be a difficult process to come to terms with.
- **Relearning your 'normal':** Some people describe having to relearn their body and the way it works. You might find that you are worried about pain or sensations which you previously considered normal, or find that you want reassurance from your treatment team over what is normal for you.

It can help to discuss these feelings with other people who have been through a similar experience. You can find more information in the 'What support is available' section of this booklet.



What support is available to me locally?

*"Treatment for head and neck sarcoma can affect fundamental parts of your day to day life."*

# What support is available?



How do I access rehabilitation services?

There are many services which can support you throughout your treatment and recovery.

## Physical support and rehabilitation:

More information on physical support and rehabilitation can be found in the 'What if my treatment affects my...?' section of this booklet, or the Sarcoma UK 'Understanding Rehabilitation and Life After Treatment' booklet.

Rehabilitation for head and neck sarcoma can involve the services of:

- Speech and language therapists
- Dieticians
- Physiotherapists
- Psychological or counselling services
- Clinical nurse specialists
- Dental services, who might provide advice on mouth care and hygiene.

*"Your rehabilitation may focus on a specific area, such as voice restoration or swallowing"*

Your rehabilitation may focus on a specific area, such as voice restoration or swallowing, or it may be broader and encompass many aspects of recovery. If you have any questions about any aspect of your physical recovery, you can ask your Clinical Nurse Specialist who will be able to provide you with more information.

## Emotional and psychological support:

It can be helpful to talk to someone about how you are feeling. Your Clinical Nurse Specialist can give you more information.

- Sarcoma UK run a Support Line, which offers independent confidential advice and support. Our Support Line is available to anyone who has been affected by sarcoma. You can contact us by phone on **0808 801 0401** or by email at [supportline@sarcoma.org.uk](mailto:supportline@sarcoma.org.uk)
- There are a number of Sarcoma Support Groups across the country. These provide support and information to patients, carers and family members, and provide an opportunity to meet locally and informally. [www.sarcoma.org.uk](http://www.sarcoma.org.uk)
- Sarcoma UK has an information booklet with practical steps on how to cope with treatment and recovery, called 'Rehabilitation and Life After Treatment'. It can be accessed on the Sarcoma UK website or ordered as a print copy.
- Maggie's Centres provide support and advice through a team of cancer support specialists, benefits advisors, nutritionists, psychologists and therapists. They have 21 centres across the UK, and can offer support online at: [www.maggiescentres.org.uk](http://www.maggiescentres.org.uk)
- Macmillan Cancer Support offer support services within hospital cancer centres and across the community. More information can be found at: [www.macmillan.org.uk](http://www.macmillan.org.uk)
- The Professional Standards Authority provide information on all accredited counselling and psychotherapy services in the UK. More information can be found on their website: [www.professionalstandards.org.uk](http://www.professionalstandards.org.uk)

*"There are also a range of charities aimed at helping people come to terms with head and neck surgery."*

#### Head and neck specific support:

There are also a range of charities aimed at helping people come to terms with head and neck surgery. These recognise the fact that head and neck sarcoma can feel very different to other types of cancer, and aim to provide support to deal with this.

*“The Patient Advice and Liaison Service (PALS) offers confidential advice and information about healthcare related issues.”*

- Changing Faces is the leading UK charity for people in the UK with a visible difference – a mark, scar or condition which affects the way they look. They provide advice, support and psychosocial services for children, young people and adults. More information can be found here: <https://www.changingfaces.org.uk>
- Oracle Cancer Trust fund research into head and neck cancer. They recently merged with the Heads Up cancer charity. More information can be found here: [www.oraclecancertrust.org](http://www.oraclecancertrust.org)
- Head and Neck Cancer UK is a charity set up by head and neck specialists and survivors. [www.hancuk.org/](http://www.hancuk.org/)

*What if I am struggling to get the help I need?*

If you feel that you are not getting the right support or you are not getting access to the support you need, there are a number of services that can help:

*If you feel that you are not receiving the support you need, there are a number of services that can help:*

The Patient Advice and Liaison Service (PALS) offers confidential advice and information about healthcare related issues. PALS can help resolve concerns or provide information about the NHS complaints procedure. You can find PALS at your local NHS hospital.

If you have any challenges getting support, the Citizens Advice Bureau can provide free and impartial advice. You can visit their website for information and to find the closest centre to you.

Advocacy services can provide help to ensure your voice is heard. These services may give advice about ways to have more say in your care. There are many different advocacy services available, including Support Empower Advocate Promote [www.seap.org.uk](http://www.seap.org.uk) and POhWER [www.pohwer.net](http://www.pohwer.net)

### Getting financial support:

Taking time away from work for treatment and recovery can affect your finances. There might also be additional expenses to factor in, such as childcare or travel. There are a number of services which aim to help with this:

#### Grants and Benefit entitlement

Your sarcoma Clinical Nurse Specialist should be able to advise you on the types of benefits you can claim, or on any special funding you are eligible to apply for.

Your local Citizens Advice Bureau can also give you benefits information, and many branches can help you fill out application forms.

Macmillan Cancer Support have a number of benefit advisors who offer financial advice and support to cancer patients.

#### Free prescriptions

Patients who are being treated for cancer in England can apply for a medical exemption (MedEx) certificate, which will allow you to get free prescriptions. You can get an application form from your doctor and it will need to be countersigned by your GP or consultant. Prescriptions are free for all patients in Scotland, Wales and Northern Ireland.

*"Macmillan Cancer Support have a number of benefit advisors who offer financial advice and support"*

# My diagnosis details

**Date of diagnosis**

**Details of diagnosis (type of sarcoma)**

**Treatment plan**

## My sarcoma multi-disciplinary team (MDT)

You can use this space to keep the contact details of your team members who will be involved in your treatment. You may not see all the healthcare professionals listed below.

### Key Worker/Clinical Nurse Specialist (CNS)

Offers support and advice, and acts as an important point of contact for patients when they have a concern.

**Name**

**Direct telephone**

**Email**

**Notes**

## Oncologist

A doctor who specialises in cancer treatments other than surgery, for example, chemotherapy or radiotherapy.

**Name**

**Direct telephone**

**Email**

**Notes**



## Radiologist

A doctor who specialises in diagnosing medical conditions through images, for example, x-rays.

**Notes**

## Surgeon

Treats cancer through the removal of tumours.

**Name**

**Direct telephone**

**Email**

**Notes**

## Physiotherapist

Advises on exercises to help with rehabilitation before, during and after treatment with surgery, radiotherapy and chemotherapy.

**Name**

**Direct telephone**

**Email**

**Notes**

## Occupational Therapist

Advises on activities of daily life and equipment to assist recovery and independent living. Also works with local social services to ensure patients are properly supported once they leave hospital.

**Name**

**Direct telephone**

**Email**

**Notes**

### Other professionals

You can record the contact details of other professionals you come into contact with in the space below. These may include a dietician, psychologist or social worker.

<b>Name</b>	<b>Contact details and notes</b>

**Name**

**Contact details and notes**

### Appointment diary

You can keep track of your hospital appointments by recording them in the space below.

Date	Hospital	Appointment/Treatment

Date	Hospital	Appointment/Treatment

**This booklet has been produced by the Information and Support Team at Sarcoma UK. It has been reviewed by Sarcoma UK's Information Review Panel which includes healthcare professionals and people affected by sarcoma.**

References to the source of information used to write this booklet and an acknowledgement of the members of the Information Review Panel who reviewed the booklet are available from Sarcoma UK – [info@sarcoma.org.uk](mailto:info@sarcoma.org.uk)

**Sarcoma UK** makes every reasonable effort to ensure that the information we provide is up-to-date, accurate and unbiased. We hope this booklet adds to the medical advice you have received and helps you make informed decisions about your care and treatment. Please speak to a member of your care team if you are worried about any medical issues. Sarcoma UK does not necessarily endorse the services provided by the organisations listed in our publications.



**Sarcoma**UK

The bone & soft tissue  
cancer charity

**Sarcoma UK is a national  
charity that funds vital  
research, offers support for  
anyone affected by  
sarcoma cancer and  
campaigns for better  
treatments.**

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