

# Understanding bone sarcoma



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



The bone & soft tissue cancer charity

# Contents

## About this booklet

This booklet is aimed at anyone who has been diagnosed with a bone sarcoma. It explains what bone sarcoma is, how it is diagnosed and the treatment options available to you. It also has information on where you can go for support. It is your personal guide with space available to keep all your diagnosis information and the details of your next hospital appointments. You can also include contact details of your doctor, sarcoma clinical nurse specialist or other health professionals.

You may find it useful to share the information in this booklet with your partner or family members to help them understand about bone sarcoma. If you have questions about anything you read in this booklet please contact Sarcoma UK. We offer information, support and a signposting service to other organisations that can help.

**Treatment may vary depending on which nation of the UK you live in. Please ask your doctor or sarcoma clinical nurse specialist about the treatment options available in your area.**

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This booklet was produced by **Sarcoma UK**, the only charity in the UK focusing on all types of sarcoma. Our mission is to increase knowledge and awareness of sarcoma through ground-breaking programmes that inspire involvement and transform the landscape for everyone affected by sarcoma. We:

- Raise sarcoma **awareness** to initiate change and improve standards of treatment and care
- Seek answers through **research**
- Provide **support & information** for the sarcoma community

## Sarcoma UK

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

 020 7250 8271

 [info@sarcoma.org.uk](mailto:info@sarcoma.org.uk)

**We rely solely on your donations to keep producing these booklets. Any donation is welcome:**

**Online** [sarcoma.org.uk](http://sarcoma.org.uk)  
**By cheque** payable to 'Sarcoma UK' and send to:  
Sarcoma UK,  
49-51 East Road,  
London, N1 6AH  
**By phone** 020 7250 8271

## Symbols used in this booklet

 **Look on our website for more information:**  
[sarcoma.org.uk](http://sarcoma.org.uk)

 **Questions you might consider asking your doctor or sarcoma clinical nurse specialist?**

## What is bone sarcoma?

Bone sarcoma is a cancer that starts in the bone. Sometimes a bone sarcoma is called a primary bone cancer. It is extremely rare and makes up only 0.2% of all cancer diagnoses in England. There are on average, 500 diagnoses in the UK each year.

Bone sarcoma can affect any bone in the body but the most common area it affects is the legs.

The four most common types of bone sarcoma are:

- **Chondrosarcoma**

Chondrosarcoma develops in the cartilage cells. It mostly affects adults above the age of 40 and the most common sites are the upper arm, pelvis and thigh bone. They make up 37% of all bone sarcoma diagnoses

- **Osteosarcoma**

Osteosarcoma is mostly diagnosed in teenagers and young people; however, it can also affect older adults. It mostly affects the knee, thigh bone, shin bone or upper arm. They make up 30% of all bone sarcoma diagnoses

- **Ewing's sarcoma**

Ewing's sarcoma makes up 14% of all bone sarcoma diagnoses. It most commonly affects teenagers and young adults with the pelvis, thigh bone and shin bone being the most commonly affected areas. In rare cases, Ewing's sarcoma can develop in the soft tissue around the bone, this is called soft tissue sarcoma. It is sometimes called extrasosseous sarcoma – extra means outside, osseous means bone. Ewing's sarcoma can also start in subcutaneous tissue, this means beneath the skin.

- **Chordoma**

Chordoma makes up only 6% of all bone sarcoma diagnoses and most commonly affects adults in their 40's and 50's. The majority of chordomas (50%) arise in the sacrum (the bottom of the spine); however, 30% arise at the base of the skull and the remaining 20% arise in other locations in the spine.



“Bone sarcoma is extremely rare and makes up only 0.2% of all cancer diagnoses in England.”

## What are the signs and symptoms of bone sarcoma?

Symptoms of bone sarcoma can vary depending on the size and location of your tumour.

The most common signs are:

- Bone pain, particularly occurring at night
- A mass or swelling
- Restricted movement in a joint

Symptoms can sometimes be confused with more common problems such as a sports injury or in children and young people, growing pains.

“Symptoms can sometimes be confused with more common problems such as a sports injury or in children and young people, growing pains..”

## How is bone sarcoma diagnosed?

A diagnosis of bone sarcoma usually starts with a visit to your GP who will refer you for an x-ray. If a bone sarcoma is suspected following the results of the x-ray your GP will refer you to a specialist bone sarcoma centre.

Your symptoms will then be investigated further by a specialist doctor using a series of tests that may identify sarcoma. Tests may include:

- Physical examination
- A scan - taking pictures of inside the body using x-ray, CT, PET or MRI
- A biopsy – taking and testing a tissue sample

## Types of diagnostic scans and tests

### X-ray

Uses x-radiation to take images of dense tissues inside the body such as bones or tumours.

### CT

The Computer Tomography (CT) scan takes a number of x-rays to make a 3D image of an affected area.

### PET

The Positron Emission Tomography (PET) scan shows up changes in tissues that use glucose as their main source of energy – for example, the brain or heart muscle. It involves an injection of a very small amount of a radioactive drug into the body. The drug travels to places where glucose is used for energy and shows up cancers because they use glucose in a different way from normal tissue.

### MRI

Magnetic Resonance Imaging (MRI) uses magnets to create an image of the tissues of the body.

“PET scans shows up changes in tissues that use glucose as their main source of energy.”

### Bone scan

Uses radioactive chemicals called radionuclides which are injected, swallowed or breathed into the body, to take images of bones.

### Histopathology

Examination of a tissue by a pathologist under a microscope to identify disease.

### Blood test

Laboratory analysis of a blood sample.

## Understanding your diagnosis

A diagnosis of bone sarcoma should be confirmed by a specialist sarcoma pathologist who will identify the type of sarcoma and the stage and grade of the tumour. Identifying the stage and grade of a cancer means your doctor can advise on the best course of treatment for you. It also describes the cancer in a common language which is useful when your doctor is discussing your case with other doctors or health 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 the grade of the cancer.

### Grading

Low-grade means that the cancer cells are slow-growing and look quite similar to normal cells. They are less aggressive and less likely to spread.

High-grade means the cancer cells are fast growing and look

“Identifying the stage and grade of a cancer means your doctor can advise on the best course of treatment for you.”

very abnormal. They are more aggressive and more likely to spread.

## Staging

### Stage 1

The cancer is low-grade and has not grown outside the bone.

Stage 1 is further divided into:

- 1a** The cancer is low-grade and is still completely within the bone it started in.
- 1b** The cancer is low-grade and has grown through the bone wall.

### Stage 2

The cancer is high-grade and has spread beyond the bone.

Stage 2 is further divided into:

- 2a** The cancer is high-grade and is still completely in the bone it started in.
- 2b** The cancer is high-grade and has grown outside the bone wall.

### Stage 3

The cancer may be any grade and has spread to another part of the body, such as the lungs.

## Who will treat me?

The National Institute for Health and Care Excellence (NICE) recommends that anyone with sarcoma should be referred to a specialist sarcoma team for diagnosis and treatment. There

are five national bone sarcoma centres in England and Wales where all bone sarcoma patients should be treated.

These are located in Newcastle, Manchester & Oswestry, Birmingham, Oxford and London. People in Northern Ireland will usually travel to Birmingham for treatment. People in Scotland will be treated in Glasgow, Edinburgh, Aberdeen, Dundee and Inverness. This may mean you will have to travel some distance for your treatment. Some treatments like radiotherapy or chemotherapy may be given in your local hospital under the supervision of the specialist sarcoma centre.

Your case will be managed by a team of experts from a wide range of health care professions called a multidisciplinary team (MDT). Your MDT will include your key worker or sarcoma clinical nurse specialist, surgeon and other healthcare professionals involved in your care.

## What treatment is available?

The treatment you will receive depends on the type of bone sarcoma you have and which part of the body is affected. Your MDT will discuss your case and your doctor or nurse will talk you through your options so you are included in deciding what treatment is best for you.

### Chondrosarcoma

#### Chondrosarcoma Surgery

The first treatment method for chondrosarcoma is usually surgery. The surgeon will remove the tumour and will aim to

**?** What is the stage and grade of my bone sarcoma?

**?** Who is my sarcoma clinical nurse specialist?

**!** Contact Sarcoma UK for more information on high-volume centres

“Your MDT will discuss your case and your doctor or nurse will talk you through your options.”

“Tumours in the pelvis can sometimes be hard to remove with surgery.”

take out an area of normal tissue around it too. This is known as taking a margin. To achieve this margin of normal tissue, some patients will receive limb-sparing surgery. The aim of this surgery is to preserve the limb where the tumour is rather than amputating it. Limb-sparing surgery involves taking out the affected bone and replacing it with a bone graft (bone taken from another part of the body). Unfortunately, it's not always possible to use limb-sparing surgery. Sometimes the cancer may spread from the bone to the nerves and blood vessels around it. If this happens the only way to treat the cancer may be to remove part of the limb known as a partial amputation. Some people may need to have all of their limb removed. This is called a full amputation.

Tumours in the pelvis can sometimes be hard to remove with surgery. You may be given chemotherapy first, then surgery to get rid of all of the cancer. You may also receive radiotherapy after surgery to get rid of any cancer cells still in the area. Pelvic bones can sometimes be reconstructed after surgery, either by a bone graft or using a prosthesis. Unfortunately, in some cases pelvic bones and the leg they are attached to might need to be removed, this is called a hind-quarter amputation.

For a tumour in the lower jaw bone, the entire lower half of the jaw may be removed. This may be reconstructed using bones from other parts of the body. If the surgeon can't remove all of the tumour, radiation therapy may be used as well.

If your tumour is in the spine or the skull, it may not be possible to remove all of the tumour safely. Sarcoma in

these bones may require a combination of treatments such as chemotherapy, surgery, and radiation.

### Chondrosarcoma Chemotherapy

Chemotherapy uses anti-cancer drugs to destroy cancer cells. Some chondrosarcoma tumours may respond to chemotherapy. You may be treated with chemotherapy before surgery to reduce the size of the tumour so it can be operated on and removed safely. It is also sometimes used after surgery. In this case, the aim is to kill off any local cancer cells which remain in the area of the tumour.

### Chondrosarcoma Radiotherapy

Radiotherapy uses high-energy radiation beams to destroy cancer cells. Chondrosarcoma is not usually sensitive to radiotherapy; however, this type of treatment may be used after surgery in some cases, if there is a risk that the cancer has spread to the surrounding soft tissue.

“Chondrosarcoma is not usually sensitive to radiotherapy.”

## Osteosarcoma

The main treatments for osteosarcoma are surgery and chemotherapy.

### Osteosarcoma Surgery

During surgery, the surgeon will remove the tumour and will aim to take out an area of normal tissue around it too; this is known as taking a margin. The surgeon will aim to take out the tumour and maintain as much limb function as possible. To achieve this margin of normal tissue, some

“The surgeon will aim to take out the tumour and maintain as much limb function as possible.”

patients will receive limb-sparing surgery. The aim of this surgery is to preserve the limb where the tumour is rather than amputating it. Limb-sparing surgery involves taking out the affected bone and replacing it with a bone graft (bone taken from another part of the body). Unfortunately, it's not always possible to use limb-sparing surgery. Sometimes the cancer may spread from the bone to the nerves and blood vessels around it. If this happens the only way to treat cancer may be to remove part of the limb known as a partial amputation. Some people may need to have all of their limb removed. This is called a full amputation.

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If your tumour is in the spine or the skull, it may not be possible to remove all of the tumour safely. Sarcoma in these bones may require a combination of treatments such as chemotherapy, surgery, and radiation.

## Osteosarcoma **Chemotherapy**

Chemotherapy uses anti-cancer drugs to destroy cancer cells. It is sometimes used before surgery to reduce the size of the tumour so it can be operated on and removed. This can be useful to treat large tumours and can prevent the need to have the limb either partially or fully amputated. Chemotherapy is also sometimes used after surgery. In this case, the aim is to kill off any local cancer cells which remain in the area of the tumour. The main types of chemotherapy used to treat osteosarcoma are doxorubicin, cisplatin, high-dose methotrexate and ifosfamide.

Children, adolescents and young adults (aged 30 or under) may also be given a course of a new drug called mifamurtide (Mepact) which may help to reduce the risk of osteosarcoma coming back. This treatment is not relevant for everyone; however, children, adolescents and young adults should be able to have mifamurtide if:

- Their tumour is high grade and has not spread to another part of the body
- and**
- They have had an operation to remove their tumour
- and**
- They are also having chemotherapy with multiple drugs

## Osteosarcoma **Radiotherapy**

Radiotherapy uses high-energy radiation beams to destroy cancer cells. Osteosarcoma is not always sensitive to radiotherapy; however, this type of treatment may be used after surgery in some cases, if there is a risk that the cancer has spread to the surrounding soft tissue.

“Children, adolescents and young adults with osteosarcoma may also be given a course of a new drug called mifamurtide (Mepact).”

“The first treatment method for Ewing’s sarcoma is chemotherapy.”

## Ewing’s sarcoma

### Ewing’s sarcoma Chemotherapy

The first treatment method for Ewing’s sarcoma is chemotherapy. Chemotherapy uses anti-cancer drugs to destroy cancer cells. It is sometimes used before surgery to reduce the size of the tumour so it can be operated on and removed. This can be useful to treat large tumours and can prevent the need to have the limb either partially or fully amputated. Chemotherapy is also sometimes used after surgery. In this case, the aim is to kill off any local cancer cells which remain in the area of the tumour. The main types of chemotherapy used to treat Ewing’s sarcoma are doxorubicin, cyclophosphamide, ifosfamide, vincristine, dactinomycin and etoposide. These are often used in combination for example, VIDE which is a combination of vincristine, ifosfamide, doxorubicin and etoposide.

### Ewing’s sarcoma Surgery

Once the tumour has shrunk down with chemotherapy, the team treating you will consider whether or not any residual tumour should be removed surgically. In general, the best way to control the tumour is to operate. The surgeon will aim to take out the tumour and maintain as much limb function as possible. To achieve this margin of normal tissue, some patients will receive limb-sparing surgery. The aim of this surgery is to preserve the limb where the tumour is rather than amputating it. Limb-sparing surgery involves taking out the affected bone and replacing it with a bone graft (bone taken from another part of the body). Unfortunately, it’s not always possible to use limb-sparing surgery. Sometimes the cancer may spread from the bone to the nerves and

blood vessels around it. If this happens the only way to treat cancer may be to remove part of the limb known as a partial amputation. Some people may need to have all of their limb removed. This is called a full amputation.

Tumours in the pelvis can sometimes be hard to remove with surgery. You may be given chemotherapy first, then surgery to get rid of all of the cancer. You may also receive radiotherapy after surgery to get rid of any cancer cells still in the area. Pelvic bones can sometimes be reconstructed after surgery, either by a bone graft or using a prosthesis. Unfortunately, in some cases pelvic bones and the leg they are attached to might need to be removed, this is called a hind-quarter amputation.

For a tumour in the lower jaw bone, the entire lower half of the jaw may be removed. This may be reconstructed using bones from other parts of the body. If the surgeon can’t remove all of the tumour, radiation therapy may be used as well.

If your tumour is in the spine or the skull, it may not be possible to remove all of the tumour safely. Sarcoma in these bones may require a combination of treatments such as chemotherapy, surgery, and radiation.

### Ewing’s sarcoma Radiotherapy

Radiotherapy uses high-energy radiation beams to destroy cancer cells. It is effective in treating Ewing’s sarcoma and can be used before or after surgery. When used before surgery it aims to reduce the size of the tumour so it can be operated on and removed. When used after surgery, the aim is to kill off any local cancer cells that remain in the area of

“Radiotherapy is effective in treating Ewing’s sarcoma and can be used before or after surgery.”

the tumour. It is sometimes used alongside chemotherapy, particularly if the tumour is in a site where removing it surgically is very difficult or surgery may be very disabling.

## Chordoma

The treatment for chordoma depends on the size and location of your tumour.

### Chordoma Surgery

The first treatment method for chordoma is surgery. The surgeon will remove the tumour and will aim to take out an area of normal tissue around it too; this is known as taking a margin. Sometimes surgery for chordoma cannot involve

taking a margin of normal tissue due to the tumour's location, so in these cases, the margins of the removed tissue will show tumour cells when viewed under a microscope. Radiotherapy will be given after surgery to kill off any local cancer cells left in the area of your tumour, including those not visible microscopically. If there are nerves and arteries involved and they cannot be removed along with the tumour, then the aim of the surgeon will be to reduce the size of the tumour so radiotherapy treatment after surgery will be more successful. If your tumour cannot be operated on then radiotherapy alone will be the treatment of choice.

Some surgery for sarcoma may have some impact on your quality of life afterwards. Spinal surgery may affect how your bowel or bladder works or how your legs work. Surgery in the sacrum may involve the removal of nerves that work the bowel or bladder. This may lead to some people needing a

colostomy or urostomy following surgery. You will be told of any potential risks involved before you have surgery.

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 alternatives. You should also have the opportunity to ask any questions you may have regarding the future implications of your surgery. Please speak to your doctor or sarcoma clinical nurse specialist if you have any concerns about your treatment.

### Chordoma Radiotherapy

Radiotherapy uses high-energy radiation beams to destroy cancer cells. It is used in the treatment of chordoma after surgery to kill off any local cancer cells that are left in the area. It will also be used after surgery if your tumour has only been partially removed. If your tumour cannot be operated on then radiotherapy alone will be the treatment of choice.

There are newer methods of radiotherapy that are sometime used to treat chordoma. Stereotactic radiotherapy, image-guided radiotherapy (IGRT) and intensity-modulated radiotherapy (IMRT) all allow doctors to direct higher doses of radiation more accurately at the tumour and minimise the side effects of treatment.

Proton beam therapy can be effective in treating chordoma. It is a different type of radiotherapy that uses high-energy protons rather than high-energy radiation to deliver a dose of radiotherapy. Proton beam therapy can be more effective than regular radiotherapy as it can be

A colostomy is formed during surgery to divert a section of the large intestine (colon) through an opening in the abdomen (tummy). The opening is known as a stoma. A pouch is placed over the stoma to collect waste products that would usually pass through the colon and out of the body through the anus (back passage).

The surgeon operating on you should have relevant expertise in performing surgery in the location of your tumour. An orthopaedic surgeon will operate on chordoma in the sacrum whereas a neurosurgeon or spinal surgeon will perform surgery on the spine.



How will my surgery affect my quality of life afterwards?

From 2018, proton beam therapy will be offered to selected sarcoma patients at the Christie NHS Foundation Trust in Manchester and University College London Hospitals NHS Foundation Trust.

delivered precisely to where it is needed. This reduces the risk of damage to the surrounding tissue or vital organs. It is not currently available in the UK; however, the NHS will pay for selected patients (including some sarcoma patients) to receive this type of treatment overseas (in the USA or Europe).

### Chordoma Chemotherapy

Chemotherapy uses anti-cancer drugs to destroy cancer cells. It has not been shown to be effective in treating chordoma; however, it is sometimes used to control chordoma that has come back after initial treatment (recurred) or spread to another part of the body (metastasised).

## What happens after I have had my treatment?

After treatment you will have regular follow-up appointments for several years. These appointments are designed to look for signs of your cancer returning or signs that it has spread to another part of the body. You should receive a follow-up schedule from your sarcoma clinical nurse specialist. The usual practice will include:

- A chance to discuss symptoms
- An assessment of the function of any reconstruction, such as a prosthesis or bone graft, and a look at any complications that may have arisen following surgery
- A physical examination and CT or MRI to look for any signs of your sarcoma returning
- A chest x-ray to look for any secondary cancers occurring in the lungs

“After treatment you will have regular follow-up appointments for several years.”

## Will my cancer come back?

Sarcoma cancer can reappear in the same area after treatment of a previous tumour; this is called a local recurrence.

If the cancer does reappear, it is important to get treated as quickly as possible. This could involve further surgery, radiotherapy and/or chemotherapy; your treatment will be assessed on an individual basis. It is useful to check for recurrences yourself through self-examination – your doctor or sarcoma clinical nurse specialist can tell you what to look for.

If you are worried about your cancer returning contact your doctor or sarcoma 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 cancer may appear in other parts of the body. This is called a metastasis or secondary cancer. In people with bone sarcoma, these secondary cancers may appear in the lungs. A chest x-ray is taken at follow-up appointments to look for secondary cancers in the lung.

Treatment for secondary cancers may involve surgery, radiotherapy or chemotherapy as appropriate; your treatment will be assessed on an individual basis.

“If you are worried about your cancer returning contact your doctor or sarcoma clinical nurse specialist.”

# What support is available?

## Rehabilitation services

After treatment for sarcoma you may benefit from rehabilitation services. They can offer specialist advice and treatment that aids your recovery and helps you to deal with the effects of cancer and its treatment.

Rehabilitation services include:

### **Occupational therapy**

Occupational therapists assess your ability to carry out daily living activities such as washing, dressing and meal preparation. They can also help you return to normal daily activities such as work, parenting, and leisure activities.

### **Physiotherapy**

Physiotherapists help you return to as active a lifestyle as possible. They will help you strengthen your muscles and ensure your joints regain as much mobility as they can. This may involve designing a special exercise programme, providing advice about managing tiredness or teaching you to use equipment to help you walk or to support your joints.

### **Dietary services**

Dieticians assess whether you need any special diet and can advise on the most appropriate nutritional support to help you before, during and after treatment.

### **Orthotics and prosthetics**

After surgery for bone sarcoma you may need aids to help you. For example, an orthotist can help by providing you

with supports or splints. If you have had an amputation, a prosthetist can assess and fit an artificial limb.

Rehabilitation usually starts after treatment. However, with bone sarcoma you may find that it helps to start rehabilitation earlier. Ask your sarcoma clinical nurse specialist or doctor to refer you to the rehabilitation team. You may find that you are not automatically offered a referral to rehabilitation services by your medical team, so it is important to ask at the earliest opportunity for a referral.

## Emotional support

### **Talking about it**

A diagnosis of cancer can be frightening. There is no right or wrong way to feel or react to diagnosis; you may feel angry, sad or anxious about the future. You may also have concerns for how the news will affect your loved ones. You may find comfort in talking about your concerns with family members or friends.

### **Talking to others affected by bone sarcoma**

If you do not feel comfortable discussing your concerns with family or friends, it may help to talk to other people who have been affected by sarcoma. There are a number of sarcoma support groups [sarcoma.org.uk/support-groups](https://www.sarcoma.org.uk/support-groups) supported by Sarcoma UK around the country. These offer valuable support and information to patients, carers and family members, and provide the opportunity to meet with other people in the same situation.

Most groups are run by patients and carers working together with local sarcoma clinical nurse specialists or doctors. A

! Find out more about rehabilitation services at [sarcoma.org.uk/rehabilitation](https://www.sarcoma.org.uk/rehabilitation)

? What rehabilitation services will be available to me following my treatment?

“There is no right or wrong way to feel or react to diagnosis; you may feel angry, sad or anxious about the future.”

typical meeting may include a talk from an invited speaker on a related topic, discussion and questions, informal chat with other group members, and refreshments.

There is also online support [sarcoma.org.uk/Sarcoma-UK-Online-Support-Groups](http://sarcoma.org.uk/Sarcoma-UK-Online-Support-Groups) available for people affected by all types of sarcoma. Online support provides members with the opportunity to get in touch with other sarcoma patients or carers to discuss their concerns over a new diagnosis, treatment options or worries about the future.

**Club HQ** is a national support network for sarcoma patients who have had a hindquarter amputation. They offer information, mentoring, support and annual get-togethers to share and discuss experiences.

Tel: 0113 258 5934 Email: [info@bcrt.org.uk](mailto:info@bcrt.org.uk)

### ***Talking to a professional***

You may find it helpful to talk to your sarcoma clinical nurse specialist or doctor about your diagnosis; they will be able to answer any questions you may have about your condition. They may also be able to put you in touch with a counsellor for additional support, providing you with a safe, confidential place to talk about your concerns. Your GP will have access to local counselling services who can provide support to people with cancer.

## **Practical support**

### ***Free prescriptions***

Patients who are being treated for cancer 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.

### ***Benefit entitlement***

Your sarcoma clinical nurse specialist should be able to advise you on the types of benefits you can claim or any special funding you can 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 including advice about returning to work following cancer treatment.

“Your local Citizens Advice Bureau can give you benefits information.”

 **Find out more about support groups on our website**

# My diagnosis details

## Date of diagnosis

## Details of diagnosis

## 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

## 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

### Prosthetist

Provides care for anyone who requires an artificial replacement for a lost limb called a prosthesis. They design and select the best possible prosthesis for the patient and make adjustments to maximise its performance during the fitting.

Name

Direct telephone

Email

Notes

### Orthotist

Provides care for anyone who requires an orthosis, a device to support or control part of the body such as splints, braces and special footwear. Orthoses aid movement and relieve discomfort.

Name

Direct telephone

Email

Notes

### Radiologist

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

Notes

### Radiographer

Takes images, such as x-rays, and may also give radiotherapy as a treatment.

Notes

### Pathologist

A doctor who identifies diseases by studying tissue samples.

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.

Name

Contact details and notes

Name	Contact details and notes

### Other professionals continued

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# sarcoma.org.uk



The bone & soft tissue cancer charity



[supportline@sarcoma.org.uk](mailto:supportline@sarcoma.org.uk)



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



020 7250 8271



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@Sarcoma\_UK



[uk.sarcoma](https://www.facebook.com/uk.sarcoma)



49-51 East Road, London N1 6AH



The  
Information  
Standard

Certified member

This organisation has been certified as a producer of reliable health and social care information.

[www.theinformationstandard.org](http://www.theinformationstandard.org)

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