



# Understanding rehabilitation and life after treatment

[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 who has a diagnosis of sarcoma.

Whether you're about to start treatment, having treatment or recovering after treatment, this booklet can provide you with information about recovery and support. It explains what rehabilitation is and what services might be available to you.

The aim of this booklet is to provide information about every stage of your rehabilitation process. Even if something does not feel relevant currently, it may be useful to refer to in the future. You might want to skip between sections, use the booklet for reference or read only the most relevant sections.

If you are a partner, family member or friend of someone with a sarcoma diagnosis, you might also find the information in this booklet useful. It is designed to provide more information about rehabilitation, and to help patients and families prepare for this period.

If you have any questions about anything you read in this booklet, please contact Sarcoma UK's Support Line on 0808 801 0401 or

[supportline@sarcoma.org.uk](mailto:supportline@sarcoma.org.uk). We offer information, support and a signposting service to organisations which can help.

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.**

# Contents

Sarcoma and treatment	4
<b>Before treatment</b>	<b>5</b>
- How do I prepare for my treatment?	6
- When can I start preparing for my treatment?	7
- Where can I get help to prepare for my treatment?	7
- What can I do before my treatment?	10
- How do I prepare emotionally/psychologically?	13
- Fertility and treatment	16
- What should I ask before my treatment?	17
<b>During treatment</b>	<b>19</b>
- What is rehabilitation	20
- What type of rehabilitation should I expect?	21
- When does rehabilitation happen?	25
- What to expect emotionally during my treatment?	26
- Where will my rehabilitation take place?	27
- What should I ask before I'm discharged?	28
<b>After treatment</b>	<b>29</b>
- What should I expect when I get home?	30
- Follow up	36
- What to watch out for	38
- What if I'm struggling to get the help I need?	39
- Getting financial support	41
<b>Glossary</b>	<b>42</b>
<b>My diagnosis details</b>	<b>46</b>
<b>My multi-disciplinary team (MDT)</b>	<b>47</b>

# Sarcoma and treatment

*“Your form of treatment will be dependent on your subtype of sarcoma.”*

If you have been diagnosed with a sarcoma, you may already know that it is a rare form of cancer which can develop in the muscle, bone, nerve cartilage, blood vessels and the fatty and fibrous tissues.

The most common treatment for sarcoma is surgery. However, radiotherapy and chemotherapy are also common, and sometimes a combination of all three will be used. Your form of treatment will be dependent on your subtype of sarcoma. You can find more information about available treatments on our website or in our Sarcoma Patient Guides.

After your diagnosis, you might find that you focus on information about your specific course of treatment. You might be concerned about how long the treatment will take, what will happen afterwards or what steps you can take to help your recovery.

While there is no right or wrong way to feel when preparing for your treatment, it is important to note that rehabilitation isn't only limited to the time after treatment. Following a process of prehabilitation before your treatment can help you prepare physically and emotionally, and can aid your recovery.

This booklet will explain how to prepare, what rehabilitation is and how these services might be useful to you.

# Before treatment

# How do I prepare for my treatment?

The time between your diagnosis and your treatment can be overwhelming.

You might have a lot of questions, or want to know what you can do to prepare.

- Your Clinical Nurse Specialist will be able to help you with this. They might speak about a period of prehabilitation or prehab. This refers to the time between your diagnosis and your treatment.
- Your prehabilitation period can be used to help you prepare physically and emotionally for your treatment. There might be specific activities which will help with this.
- Depending on your circumstance, prehabilitation might include physical activity, dietary advice or support from psychological services. Sometimes this will be structured, but this will depend on your type of sarcoma and your proposed treatment plan.

If you have any questions about this process or about a particular service, you can discuss these with your Clinical Nurse Specialist or your medical team. If you feel there is a service you would benefit from which you haven't been referred to, you can also discuss this with your medical team.

*"Your Clinical Nurse Specialist will be able to help you with any questions you may have."*

# When can I start preparing for my treatment?

The aim of a prehabilitation period is to help you start preparing for your treatment as soon as possible. In some cases, patients might follow a structured programme of prehabilitation. If this is the case for you, your medical team will advise you on when to begin.

# Where can I get help to prepare for my treatment?

There are a number of activities which can help you prepare for your treatment. Your team will help you to identify the best services for you.

## Clinical nurse specialists

When you are diagnosed with a sarcoma, you should be referred to a Clinical Nurse Specialist (CNS) for sarcoma. You will have contact with

*"When you are diagnosed with a sarcoma, you should be referred to a Clinical Nurse Specialist (CNS) for sarcoma."*

*“There are a number of activities which can help you prepare for your treatment.”*

your CNS throughout your treatment pathway, and they will be able to answer many of your questions and concerns.

#### Occupational therapy services

Occupational therapists assess your ability to carry out everyday activities such as washing, dressing and meal preparation. They can help you return to normal daily activities such as work, parenting or leisure activities. They may suggest new ways of doing things or recommend the use of special equipment.

An occupational therapist can also ask your local Social Services team to assess whether any equipment or adaptations are needed in your home and to arrange for them to be supplied.

#### Physiotherapy services

Physiotherapists help you maintain 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 specific exercise programme, providing advice about managing tiredness, or teaching you to use equipment to help you walk or to support your joints. A physiotherapist will also support you with symptom management – for example, with fatigue. They can also provide advice about physical activity.

#### Nutrition and dietetic 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.

#### Psychological/counselling services

There are many different forms of psychological and counselling services which can support you with the emotional challenges of cancer. Many hospitals have their own counselling service, which you might find it useful to access. If you find this difficult to access, or if you would like a more

**“Physiotherapists help you maintain as active a lifestyle as possible. They will help you strengthen your muscles and ensure your joints regain as much mobility as they can.”**

local service, the NHS runs a programme called Improving Access to Psychological Therapies, or IAPT, which usually involves a short course of counselling or therapy. You can ask your GP to refer you, or in some cases can refer yourself.

#### Who to speak to

Some aspects of prehabilitation – like a structured physiotherapy programme – might take place within a local hospital or Sarcoma Specialist Centre. Others might be performed individually, at home, or alongside your daily routine. If you have any questions you can contact your Clinical Nurse Specialist or the Sarcoma UK Support Line, who will be able to advise you.

You can contact our Support Line by phone on 0808 801 0401 or by email at: [supportline@sarcoma.org.uk](mailto:supportline@sarcoma.org.uk)

*“If you have any questions you can contact your Clinical Nurse Specialist or the Sarcoma UK Support Line, who will be able to advise you.”*

# What can I do before my treatment?

The ways that you prepare for your treatment will be individual to your level of health and fitness, your type of sarcoma and your treatment plan. However, there are some general steps you can take to prepare for your treatment and recovery.

## Eat well

- Eating well during your prehabilitation period can help you build up strength and energy, and help you prepare for your treatment and recovery.
- It is important to discuss your diet with your Clinical Nurse Specialist and medical team. You might be advised to follow a specialised diet, which could include extra calories or extra protein. Your CNS will also be able to advise you on how best to deal with any potential side effects – for example, if your mouth is sore or dry as a result of treatment.

## Exercise

- A physiotherapist might give you specific exercises depending on your subtype of sarcoma. It is important to follow this advice, as the exercises will help you build strength in targeted areas of your body.
- Alongside any specific exercises given to you by your physiotherapist, it is important to think about your physical activity more generally. NHS guidelines recommend that

adults between 19–64 should do 150 minutes of moderate aerobic activity (cycling, brisk walking, etc) every week. They should do strength exercises on 2 or more days.

- It is recommended that adults over 64 years should aim to be active daily. They should aim for 150 minutes of moderate activity a week, done in bouts of 10 minutes or more. (For example, this might include doing 30 minutes of exercise 5 days a week). Muscle strength exercises are recommended for 2 days a week: [www.nhs.uk/live-well/exercise/#guidelines-foradults-aged-19-to-64](http://www.nhs.uk/live-well/exercise/#guidelines-foradults-aged-19-to-64)
- If you are feeling fatigue or muscle weakness before your treatment, these guidelines might not be realistic or practical for you. However, it is worth noting the different types of activity recommended by the guidelines, and considering what you might enjoy.
- If you are already active, you should try to maintain this as much as possible. Take care not to push yourself too hard, and only do what feels comfortable for you. You might want to change the type of exercise you do, and the intensity with which you do it.
- If you feel you are not active, you should try to gently build your level of physical activity day by day, until you reach a level which feels comfortable for you. You could build physical activity gradually, with activities such as walking or gardening.
- If you have metastatic disease, it is particularly important for you to discuss any exercise with your medical team. They will be able to advise you on the best level of activity pre-treatment.

*“Think about your home environment and how you might cope when returning home.”*

*“You could build physical activity gradually, with activities such as walking or gardening.”*

## Make practical preparations for after treatment

Making practical preparations for when you finish treatment can help reassure you, and make things as easy as possible for returning home. Many patients find it useful to:

- **Prepare food/meals for after treatment**  
Eating well after surgery or treatment is really important, to help wounds heal properly and to aid your recovery. Before your treatment, you could plan meals for when you return home. Some people find it helpful to batch-cook and freeze home cooked meals, or to set up an online supermarket delivery.
- **Make practical changes to your home**  
After treatment, your movement may be restricted and you might find it more difficult to navigate your home. To manage this, you could:
  - Think about your home environment and how you might cope when returning home.
  - Remove any rugs which might be dangerous (these are the biggest cause for community falls post-treatment).
  - De-clutter spaces like hallways and bathrooms.
- **Schedule visitors**  
Friends and family will want to provide help and support. If possible, **schedule a visit from a friend or relative** in the week following your treatment.
  - Some patients find it helpful to make a list of roles for friends or families. Giving people specific jobs – such as doing the shopping, preparing and freezing meals or simply being in the house for support – can be really effective in helping everyone feel useful and more relaxed.

*“After treatment, your movement may be restricted and you might find it more difficult to navigate your home.”*

- **Make preparations for travelling home from hospital**  
After treatment, it is advised that you don't take public transport (particularly following a general anaesthetic). It is important to make sure you have an alternative way of getting home from the hospital. This might be a friend or family member to drive you, or to accompany you in a taxi. If possible, organise this before your treatment.

## How do I prepare emotionally/psychologically for my treatment?

Your treatment might focus primarily on your physical needs and capabilities. 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, 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.**

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

## “You might find it helpful to speak to a family member or friend.”

Everyone is affected differently, and every patient finds 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. There are several services which can help with this:

- 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. [sarcoma.org.uk/supportinformation/support-groups](http://sarcoma.org.uk/supportinformation/support-groups)
- Although they are not sarcoma specific, **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)

*“Sarcoma UK run a Support Line, which offers independent confidential advice and support.”*

- Macmillan 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/what-we-do/accreditedregisters/find-a-register](http://www.professionalstandards.org.uk/what-we-do/accreditedregisters/find-a-register)

### How do I cope with having treatment?

As well as coping with the overall impact of your diagnosis, you might feel anxious about beginning treatment and coping with the change in your day to day life. You can talk this through with your Clinical Nurse Specialist, who will be able to advise you.

Below are some practical steps to consider before your treatment:

- When you are in hospital, it can help to take something **which reminds you of home** or which **comforts you**. Some patients take their own pillow or pillowcase into hospital with them.
- **Taking something to do/read/listen** to can be really helpful for easing anxiety and distracting you from your surroundings, especially in waiting rooms before and after your treatment. This could include music or podcasts, which can be downloaded and saved so that they are always available to listen to.
- **Mindfulness** is a way of focusing on the present moment, and many patients find it helpful for relaxation. There are several smartphone apps which offer guided mindfulness and relaxation sessions.

*“When you are in hospital, it can help to take something which reminds you of home or which comforts you.”*

- **Stop Breathe & Think** allows you to 'check in' with your feelings, and recommends tailored sessions depending on your mood.  
[www.stopbreathethink.com](http://www.stopbreathethink.com)
- **Headspace and Calm** offer a range of guided meditations and relaxation exercises.

These are practical steps which some patients find helpful in lessening their worry or anxiety. However, if you begin to experience symptoms of anxiety more frequently or with more intensity, speak to your Clinical Nurse Specialist, who will be able to offer support.

## Fertility and treatment

Some sarcomas and treatments for sarcoma can have a negative impact on your fertility. This is largely dependent on the subtype of sarcoma and your treatment plan.

It is important to discuss fertility with your medical team, and to raise any concerns as early as possible. You could ask:

- Will any aspect of this treatment impact my fertility? If so, what are my options and how should I deal with this?

Your Clinical Nurse Specialist will be able to provide you with further information and to discuss your concerns and options.

*"Some sarcomas and treatments for sarcoma can have a negative impact on your fertility."*

## What should I ask before my treatment?

Beginning treatment can be overwhelming and you might be given a lot of information very quickly. It is helpful to write a list of any questions you have and to have them answered before your treatment starts. These could include:

- **What can I expect to be doing 2 weeks/ 6 weeks/6 months/a year after treatment?**  
This is useful to know, and can help you plan when you can get back to work/what help you might need to do so.
- **How much movement can I expect 2 weeks/ 6 weeks/6 months/a year after treatment?**  
It is important to help yourself and your family manage expectations of what you will be able to do during treatment and recovery. If you have a job which involves physical activity, it will be helpful to know what limitations you might have immediately after treatment.
- **When can I return to work?**
- **When can I drive?**
- **When can I have sex?**
- **How will the surgery/treatment affect me returning to everything I do now?**
- **Will my treatment put me at risk of lymphoedema and what can I do to avoid this?**  
More information about lymphoedema can be found on our website at [sarcoma.org.uk/support-information/patient-guides](http://sarcoma.org.uk/support-information/patient-guides)

*"It is helpful to write a list of any questions you have and to have them answered before your treatment starts."*

**“If you have a specific goal that you want to get back to, you should talk about this before your treatment.”**

If you have a specific goal that you want to get back to, you should talk about this before your treatment. This might involve your job or family commitments, and any concerns you have about returning to these.

For example, if your job is physical and requires walking or carrying heavy objects, you should ask whether this would be possible and when you should expect to return to work.

The earlier any issues are raised, the easier it will be to make preparations and adjustments. This will help you to manage expectations around your recovery, and to plan for any help you might need.

## During treatment

# What is rehabilitation?

**Rehabilitation** is a process of advice and treatment which helps you adjust to life after your sarcoma treatment or surgery.

There are many different types of rehabilitation services, and you may benefit from different services at different points of your treatment. Like the activities offered during your prehabilitation period, your rehabilitation will be very individual, and will depend on your type of sarcoma and your treatment.

*“There are many different types of rehabilitation services, and you may benefit from different services at different points of your treatment.”*

# What type of rehabilitation should I expect?

As rehabilitation is so individual to you and your treatment, it is difficult to generalise. However, it is useful to consider what forms of rehabilitation you might need to prepare for.

Below is an outline of three common treatments for sarcoma, and how rehabilitation services might be used to help your recovery following these treatments.

## What to expect if you have surgery

Surgery is one of the most common treatments for patients who have sarcoma. As surgery could involve almost any part of the body, it is difficult to give an exact list of what rehabilitation might include, but below are some ideas to consider in advance of your surgery.

- You might need walking aids, such as elbow crutches or a walking stick. The physiotherapist will assess you and provide you with an appropriate aid if one is required.
- You might be given a home exercise programme to help regain the movement in your limbs and increase your muscle strength.
- **You should be given advice on preventing swelling and stiffness in your joints and limbs.** You can discuss this with your Clinical Nurse Specialist. If your treatment has affected lymph vessels or nodes, ask your clinical nurse specialist for lymphoedema specific advice.

*“Surgery is one of the most common treatments for patients who have sarcoma.”*

You can find more advice on the Sarcoma UK website: [sarcoma.org.uk/support-information/patient-guides](https://www.sarcoma.org.uk/support-information/patient-guides)

- Scar massage should be carried out once the wound has fully healed, to prevent tightness and a loss of joint mobility. If you don't receive specific advice on this, you can ask your Clinical Nurse Specialist or physiotherapist.
- You might need specialist equipment to help you around your home. You can consider this before treatment as part of your prehabilitation. If you need specialist equipment after treatment, you can be referred to an occupational therapist.

### What to expect if you have radiotherapy

Radiotherapy treatment uses high energy radiation beams to destroy cancer cells. Your treatment for sarcoma might include radiotherapy either before or after surgery. This could involve short daily treatments over a course of several weeks.

The treatment is not painful in itself, but you might experience some side effects. Rehabilitation services can help you minimise the impact of these. Before you start radiotherapy treatment, it is worth considering:

- If you have surgery first, followed by radiotherapy, the time after surgery is especially important. It is a short window of opportunity for you to gain as much movement and muscle strength as possible before radiotherapy.
- To do this, your **physiotherapist** can teach you daily stretching exercises specific to the area being treated. These can help you to successfully maintain movement in your joints. Your physiotherapist will advise you on how frequently these exercises should be done.

- To minimise the risk of developing lymphoedema (a type of swelling), you should be given early advice on how best to care for your skin. Talk to your clinical nurse specialist or physiotherapist about this as soon as possible. Some hospitals will have a lymphoedema service, which can help with the management of lymphoedema. Your clinical nurse specialist will be able to provide more details on these.
- Remaining as active as possible throughout your treatment can help you reduce fatigue and other side effects. Try to go about your daily routine as normally as you can. You should include a daily balance of some physical activity followed by a period of rest.

### What to expect if you have chemotherapy

Chemotherapy treatment uses anti-cancer drugs to destroy cancer cells. Treatment varies depending on the type of drug, but it often involves regular visits to hospital to receive chemotherapy drugs.

Rehabilitation support before and during chemotherapy can help you to remain as active as possible. It can also help you manage any side effects. Before treatment, you should consider:

- Your physiotherapist can teach you exercises that you can do in bed or sitting in a chair, so that you can do these consistently. Ask for advice on how to maintain as active a lifestyle as possible throughout your chemotherapy.
- You might be advised to avoid group settings for exercise due to a risk of infection. You should also avoid swimming pools as these carry a high risk of infection.

*“Remaining as active as possible throughout your treatment can help you reduce fatigue and other side effects.”*

*“You might be advised to avoid group settings for exercise due to a risk of infection.”*

*“Chemotherapy can cause you to feel nauseous or for your taste in food to change. A dietician will be able to help you manage these side effects.”*

- Your occupational therapist can advise you on aids and adaptations to help you remain as independent as possible. Chemotherapy can often lead to feelings of tiredness or anxiety, and an occupational therapist will be able to advise you on dealing with this.
- Chemotherapy can cause you to feel nauseous or for your taste in food to change. You may experience a sore or dry mouth, or find you lose your appetite. A dietician will be able to help you manage these side effects, and advise on maintaining a healthy diet with appropriate nutritional support.

### Private healthcare and rehabilitation

If you are covered by private health insurance or feel that you want to be seen more quickly than on the NHS, you may consider accessing private health services.

Before approaching private practitioners, it is important that you talk to your sarcoma team and GP about which services you would benefit from most. Your sarcoma team and GP will also be able to give advice about accessing private services locally.

**“Chemotherapy can often lead to feelings of tiredness or anxiety, and an occupational therapist will be able to advise you on dealing with this.”**

## When does rehabilitation happen?

Traditionally, rehabilitation begins once you have finished a specific course of treatment. However, it is possible to begin receiving advice and support from services much earlier than this. The aim of **prehabilitation** is to prepare you for treatment as early as possible, and therefore make your recovery easier for you.

Your rehabilitation will depend on your specific subtype of sarcoma, the types of treatment you have received and how your treatment has impacted your daily life.

### Prehabilitation

The time between treatment and diagnosis, which can be used to help prepare you for your treatment.

# What to expect emotionally

When your treatment is ongoing, it can feel like everything is happening at once. Although it can be hard to deal with, you might have grown used to a routine of clinical appointments and reassurance from clinical staff. When this routine changes, it can impact different people in different ways.

- Many patients expect to feel a sense of relief when treatment ends, but this doesn't always happen. You might find that you feel scared, angry or uncertain about the future. If this is the case for you, you can speak to your Clinical Nurse Specialist about these feelings, and how best to manage them. You might also find that your feelings change naturally as you adjust back into day to day life.
- If you have any physical limitations as a result of your treatment, it is very normal to find these frustrating or upsetting. You might feel angry about what you have been through, or worried about what movement you can expect going forwards. It can be helpful to speak to other people who have experienced similar feelings or treatment, and you might consider joining a Support Group. You can find more information about Support Groups at [sarcoma.org.uk/support-groups](http://sarcoma.org.uk/support-groups).

*"It can be helpful to speak to other people who have experienced similar feelings or treatment."*

# Where will my rehabilitation take place?

Your rehabilitation can take place in various settings, including:

- At outpatient appointments before, during or after your treatment
- In hospital, while you are admitted to a ward and receiving treatment
- On a rehabilitation ward or at a specialist centre
- At your GP surgery or a local clinic
- At your home.

The location will be determined by your specific needs and the availability of local services.

It may be possible to have someone accompany you to your appointments for additional support. It might also be possible to be seen at home.

Home visits are most likely if you are less able to get out to appointments and/or if the person assessing you would like to see your home environment and how you manage in your daily life. **If receiving your treatment at a hospital far away from home, you can ask to be referred for rehabilitation at a local hospital or in your local community.**

*"It may be possible to have someone accompany you to your appointments for additional support."*

# What should I ask before I'm discharged?

It is useful to write a list of questions to ask before you are discharged from hospital or before your treatment ends. This will help to give you an idea of how your rehabilitation and recovery will progress. Some questions could include:

- When will I be seen by the community physiotherapist? How many weeks should I expect to wait?
- If I don't hear from the community rehabilitation team, who should I contact?
- What should I expect to be doing over the first few days/weeks at home?
- What level of activity should I expect to have? What should I do if this does not happen?
- If I am concerned about my level of activity, who should I speak to? How do I contact them?
- If I feel I'm not recovering as well as I should be, who should I speak to and how do I contact them?

If you have any other questions, at any time, you can ask your Clinical Nurse Specialist, who will be able to provide you with more information. You can also contact our **Sarcoma UK Support Line** by phone on 0808 801 0401 or by email at [supportline@sarcoma.org.uk](mailto:supportline@sarcoma.org.uk)

# After treatment

*"If you have any other questions, at any time, you can ask your Clinical Nurse Specialist, who will be able to provide you with more information."*

# What should I expect when I get home?

Returning home after treatment or a hospital stay can be a difficult process. Hospitals are designed with the needs of patients in mind, and many people find navigating their own homes more challenging than a hospital ward or specialist centre.

There are often more steps, levels and uneven surfaces to deal with, and home equipment is not designed with specific limitations in mind.

It is important to consider this before your treatment or surgery, so that you can make any adjustments.

- Over the first few weeks, it is completely normal to become tired and need to rest on a regular basis. Many patients find that they need a nap in the morning or afternoon.
- 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, and is part of your rehabilitation.**
- Many patients 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.
- You might find it difficult to eat, or experience side effects such as nausea, dry mouth or sore mouth which prevent you from following your

usual diet. This will largely depend on what treatment you have had, but you can seek advice from your Clinical Nurse Specialist or medical team. Although not specific to sarcoma, both the Royal Marsden Hospital and Cancer Research UK offer comprehensive guides to eating well when you have cancer, which can be found on their websites.

- It is helpful to plan your days in the first few weeks of your rehabilitation, as this helps to find a balance between resting and doing.

## What amount of movement should I expect?

It is common to feel anxious about your physical capabilities after treatment. This is particularly true after surgery.

Many people worry about how far they might be able to walk, or how easily they might be able to move. Although it is natural to worry, it might help to consider that:

- Prior to discharge, many patients will see a physiotherapist. They will be able to advise on the range of movement you can expect. If you would like to see a physiotherapist and haven't been given the option, you can discuss the option with your Clinical Nurse Specialist.
- Before leaving hospital, you might have walked a short distance – such as the length of the ward, or down a flight of stairs. If this is the case for you, then you can build on this slowly at home. Choose a short route (such as from your lounge to the front door/a hallway), and increase your distance by a small amount each day.
- Many patients find it useful to keep a diary of their progress. Recording your distances over a

*“It is completely normal to become tired and need to rest on a regular basis.”*

*“Many patients find it useful to keep a diary of their progress.”*

week can help you to track your progress, and can be encouraging when you look back.

- It can also be useful to ask a family member to keep a log or diary for you. This can help them feel they are helping your recovery, and help you to track how you have progressed over the course of your treatment.

## How should I expect to feel?

Leaving hospital can feel quite strange. The life you led before your diagnosis and surgery may seem very distant, and adjusting to a new 'normal' can take some time.

- You might feel upset, frustrated or worried about the future. You might feel guilty about feeling this way, or under pressure to appear grateful or relieved to be at home. These are all common feelings, and there is no right or wrong way to feel and act when you return home.
- Although many patients expect to feel relieved when they return home, it is normal to feel overwhelmed or anxious, or to experience emotions which you perhaps didn't recognise during your treatment. This can be upsetting for you and your family members, but it is important to have patience during your adjustment. Your Clinical Nurse Specialist will be able to help and advise you, and might suggest a counselling or psychological service while you adjust.
- Remember that returning home is a process, and that you might have good or bad days as you adjust. It might take time to feel 'normal' again. Equally, you might find that your life takes on a 'new normal', where things don't return to exactly how they were before diagnosis.

*"Although many patients expect to feel relieved when they return home, it is normal to feel overwhelmed or anxious."*

- For some patients, it is helpful to try to draw out silver linings from their treatment – perhaps a new closeness with family or friends, or an appreciation for tasks which once seemed mundane. This is usually part of a wider process of building **resilience**. For more information about resilience, speak to your CNS, who will be able to advise or refer you to services which can offer further support.
- If you are feeling angry, frustrated or alone, it might help to talk to someone who has been through a similar experience. There are **Sarcoma Support Groups** across the country, where patients, family members and friends can share experiences and support one another. More information on Support Groups can be found at [sarcoma.org.uk/support-information/support-groups](https://www.sarcoma.org.uk/support-information/support-groups)
- **Maggie's Centres** offer a 'Where Now?' course over seven weeks, which is available to anyone who has finished cancer treatment, their friends or their family. Sessions are led by a Cancer Support Specialist and Clinical Psychologist. You can find out more information from your local Maggie's Centre. [maggiescentres.org/our-centres](https://www.maggiescentres.org/our-centres)
- **Macmillan** offer a 'Life After Cancer' information booklet, which offers advice and support and can be found on their website.

## Sex, Intimacy and Relationships

When you are unwell, it is normal for the dynamics of your relationships to change. Your usual role and the things you are used to doing might not be possible while you are receiving treatment.

This might continue into your rehabilitation and recovery. If you are struggling with your relationships or to deal with this transition, it may be helpful to access emotional support.

*"Remember that returning home is a process, and that you might have good or bad days as you adjust."*

## **“As part of your transition back to daily life, it is important to be aware of any physical changes you might experience.”**

If you have any questions or concerns about sex or relationships, or feel that physical or emotional changes are making it difficult for you to adjust, your sarcoma team and Clinical Nurse Specialist will be able to provide support.

### **Managing physical changes**

As part of your transition back to daily life, it is important to be aware of any physical changes you might experience. Managing these can help make the transition easier and more comfortable for you.

### **Pain and fatigue**

- Many patients experience pain and fatigue after treatment.
- To prevent stiffness in the area that has been treated, it can be helpful to gently move the joint, or to stretch when any wounds are fully healed. However, if you are **experiencing pain or symptoms which are unusual for you**, you should talk to your Clinical Nurse Specialist as soon as possible.
- Try to give as much information as you can about what you are experiencing. It can help to write down when your symptoms started, what times of the day they occur and what activities make them better or worse.

- If you have been treated with radiotherapy or chemotherapy, you might experience other symptoms, such as **fatigue** and **memory loss**.
- It can be helpful to do light exercise to combat fatigue. You should check these with your medical team before starting.
- Once you are ready, you can gradually build up your muscle or movement by doing gentle exercise. This could be walking, swimming (if wounds are fully healed) or a gentle activity which you enjoy.
- **Make sure to talk to your Clinical Nurse Specialist or physiotherapist about any exercises.** They will be able to advise whether there are specific exercises or movements which would be helpful, or if you should avoid any movements or activities.
- If your treatment is ongoing and you are experiencing physical changes or side effects, you should speak to your Clinical Nurse Specialist and your medical team. They will be able to advise you on the best course of action for your condition.

*“Once you are ready, you can gradually build up your muscle or movement by doing gentle exercise.”*

*“Try to give as much information as you can about what you are experiencing.”*

# Follow up

Once you have recovered from surgery, your medical team will suggest a routine of follow up visits, which might take place in a local hospital or a Sarcoma Specialist Centre.

These might be every few months or quarterly, depending on your individual case.

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 a recurrence of your sarcoma, and for any metastases.**

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 run up to 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.

## Preparing for an appointment

- 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.
- If possible, **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.

- The clinical staff want you to be as comfortable and at ease as possible. If you find it difficult to wait in the clinical setting, or find that this is making you more anxious than you otherwise would be, you can explain this to the team. They will be able to help and suggest alternatives which might be easier for you.
- **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.
- **Wear clothing that is easy to remove.** The doctor might want to listen to your breathing or inspect the site of your surgery. Wearing comfortable clothes will mean you don't have to be embarrassed by having awkward clothing to take off.
- 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. There may also be a physiotherapist available, who will be able to help with any difficulties you might be having.

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

### Scanxiety

A feeling of anxiety or worry in the run up to a follow up appointment or scan.

# What to watch out for

In some cases, a sarcoma may return in the same place (recurrence) or in another part of the body (called metastasis or secondary cancer).

In sarcoma patients, metastasis can occur in the lungs, which is why your follow up appointment might involve a chest x-ray.

- One of the most common ways for sarcoma to recur is for a lump to appear close to the size of the original tumour.
- Some patients find it reassuring to check for recurrence themselves. If you want to do this, you can lightly run your fingers over and around the site of your original tumour, feeling for any new lumps or anything that you feel is not normal for you. Make sure any wounds are healed before you do this, and only do it once a month, otherwise you may begin to worry more than necessary.
- It is important to recognise what is normal and unusual for you. If something has changed or doesn't feel right for you, raise this with your Clinical Nurse Specialist as soon as possible.

Although your condition will be monitored and followed up by your medical team, **you are the most likely person to detect a recurrence of your sarcoma**. It is important to monitor your own condition and to raise any concerns as quickly as possible.

*“One of the most common ways for sarcoma to recur is for a lump to appear close to the size of the original tumour.”*

## Lymphoedema

Lymphoedema is a swelling caused by a build-up of fluid in the tissues under the skin. It can develop if your treatment for sarcoma affected your lymph nodes or vessels

- Lymphoedema can occur weeks, months or years after treatment.
- The most common symptom is a swelling in the arm or leg. Swelling is normal after radiotherapy or surgery, as this is part of the healing process. However, **if the swelling has not gone down within 6-8 weeks**, you should contact your Clinical Nurse Specialist.

# 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:

- **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

*“PALS can help resolve concerns or provide information about the NHS complaints procedure.”*

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 (SEAP) [www.seap.org.uk](http://www.seap.org.uk) and POhWER ([www.pohwer.net](http://www.pohwer.net)).
- The **Sarcoma UK Support Line** is a source of information and support. Our specialist nurses can advise you about which services should be available to you and signpost you to services which might help. They can also be a listening ear if you want to talk through any aspect of your treatment or rehabilitation. You can contact our Support Line by phone on 0808 801 0401 or by email at [supportline@sarcoma.org.uk](mailto:supportline@sarcoma.org.uk)

*“Our specialist nurses can advise you about which services should be available to you and signpost you to services which might help.”*

# 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.

*“Your sarcoma Clinical Nurse Specialist should be able to advise you on the types of benefits you can claim.”*

# Glossary

## Types of therapies and services

There are many different forms of rehabilitation therapies and services available, and it is common to benefit from a number over the course of your treatment.

### Specialist nursing

When you are diagnosed with a sarcoma, you should be referred to a Clinical Nurse Specialist (CNS) for sarcoma. You will have contact with your CNS throughout your treatment pathway, and they will be able to answer many of your questions and concerns.

As well as your CNS, you might also be referred to a different nursing team who will care for you at home or in your local community. You might be referred to these services during or after treatment. If you feel you need to be referred but haven't been, you can ask for a referral from your healthcare team.

### District nursing

District nurses (DNs) visit you at home. You may be referred before you leave hospital or by your GP. DNs can dress or look after wounds if this cannot be done at outpatient appointments. They can also administer medications and order some types of specialist equipment such as pressure relieving cushions or mattresses if required.

### Continence services

If you have bladder or bowel problems as a result of treatment you may be referred for a continence assessment. Specialist nurses and health care assistants can work with you to improve continence and alleviate symptoms where possible.

### Tissue viability services

If you have a wound or pressure area that is taking a long time to heal, tissue viability nurses can give specialist advice to help it get better. You may see a tissue viability specialist at the hospital, but your GP or district nurses may refer you if they feel you could benefit from a more specialist assessment when you are at home

### Lymphoedema services

Lymphoedema is a swelling caused by a build-up of fluid in your tissues. It can occur sometime after radiotherapy or surgery (see our lymphoedema factsheet for more information). This condition may be managed by a physiotherapist, your GP and other nursing teams. Some areas have specialist lymphoedema services.

## Occupational therapist services

Occupational therapists assess your ability to carry out everyday 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. They may suggest new ways of doing things or recommend the use of special equipment. The occupational therapist can also ask your local Social Services team to assess whether any equipment or adaptations are needed in your home and to arrange for them to be supplied.

## Physiotherapy services

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.

## Orthotics and prosthetic services

An orthotist can help by providing you with supports or splints if bones and muscles have been affected by surgery. If you have had an amputation, a prosthetist can assess and fit an artificial limb.

## Wheelchair services

You may be referred to wheelchair services if treatment has affected your mobility. Most services only provide wheelchairs for people who will need to use them frequently or for those who require specialist support however this will depend on funding in your local area.

## Nutrition and dietetic 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.

## Speech and language therapy

Speech and language therapists help with problems such as difficulties with swallowing, eating, drinking, or talking which may be a result of your cancer or treatment.

## Psychological and counselling services

Psychologists and counsellors can support you with the emotional challenges of cancer. They listen to how you are feeling and may suggest ways to improve your mood. They can also help you to build your confidence. This may also be helpful to support your family members too.

## Social services

Social services can provide a range of different types of support. You may be referred to a

social worker who will assess your needs.

This might include:

- Looking at any help you might need to do daily tasks such as washing and dressing
- Arranging a package of care which involves carers coming to visit and help with daily tasks
- Organising adaptations to your property or in some cases, rehousing
- Putting support in place if you are having difficulty caring for others
- Providing funding for a family member or friend to become a carer for you, or supporting your family members or carers.

## 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

### Pathologist

A doctor who identifies diseases by studying tissue samples.

Name

Direct telephone

Email

Notes

### Radiologist

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

Name

Direct telephone

Email

Notes

### Surgeon

Treats cancer through the removal of tumours.

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

### Radiographer

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

**Notes**

### Physiotherapist

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

**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.

**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



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**

**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**

 @Sarcoma\_UK

 @Sarcoma\_UK

 uk.sarcoma

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

Registered as a charity in England & Wales (1139869) & in Scotland (SC044260)  
A company limited by guarantee in England & Wales (7487432)