

Rehabilitation

This factsheet 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.



The bone & soft tissue cancer charity

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.

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

Rehabilitation for sarcoma patients

What rehabilitation services are available to me?

When can I start my rehabilitation?

How do I get referred to these services?

Further information

What rehabilitation services are available to me?

If you are diagnosed with a bone or soft tissue sarcoma you can benefit from specialist advice and treatment that aids your recovery and helps you to deal with the effects of cancer and its treatment.

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. 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

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.

Continued overleaf

Rehabilitation

What rehabilitation services are available to me? continued

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.

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.

Orthotics and prosthetics

The treatment of sarcoma often involves surgery. Your doctor will discuss this with you in detail, and if surgery is necessary there are various options to help you afterwards. 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.

It may be possible to have someone accompany you to your appointments for additional support, such as a family member or friend. Ask your clinical nurse specialist for more details.

When can I start my rehabilitation?

Rehabilitation usually starts after treatment. However, with sarcoma you may find that it helps to start rehabilitation earlier.

At diagnosis

Ask the sarcoma team at the hospital where you are going to have your treatment to refer you to the relevant services.

Before and after surgery

Surgery is one of the most common treatments for patients who have sarcoma. It is very helpful even before the operation to have an idea of what you may need afterwards. As surgery for a sarcoma could involve almost any part of the body, it is difficult to give an exact list of what the rehabilitation would include, but below are some ideas that you may like to consider in advance of your surgery, so that you are prepared:

- Walking aids such as elbow crutches or a walking stick
- Home exercise programme to regain the movement in your limbs and increase your muscle strength. It may also help to put in place an exercise programme before surgery or other treatment, to help you recover faster
- Advice on preventing stiffness and swelling in your joints and limbs
- Specialist massage called connective tissue massage might help with scar healing and prevent soft tissue tightness, once your wound has healed
- Physiotherapy can usually be given in the home or in an out-patient department, but sometimes it is necessary to have intensive physiotherapy as an in-patient for a short period to regain function after the surgery
- Think about whether you may need any special equipment to help you around the home and ask to be referred to the occupational therapist

During radiotherapy treatment

Radiotherapy treatment uses high energy radiation beams to destroy cancer cells. Your treatment for sarcoma might include radiotherapy either before or after surgery. This may involve short daily treatments for several weeks. The treatment is not painful in itself, however there are some side-effects which might occur and rehabilitation services can help to minimise the impact of these. Here are some things to consider before you start radiotherapy treatment:

- If you have surgery first, followed by radiotherapy, the time after the surgery is very important in that it is a short 'window of opportunity' to get as much movement and muscle strength back as possible before the radiotherapy starts
- Movement in a joint can usually be maintained successfully by doing daily stretching exercises, which your physiotherapist will teach you. These exercises should be done at least three times a day during the radiotherapy and should be continued at least once a day after the treatment has finished
- Early advice on good skin care can minimise the risk of developing lymphoedema (a type of swelling) after surgery and radiotherapy. Talk to your physiotherapist about this as soon as you can. Some hospitals will have a lymphoedema service that can help with the management of lymphoedema. Ask your clinical nurse specialist (CNS) for more details
- Aim to remain as active as possible throughout the period of radiotherapy treatment. Try to go about your daily routine as normally as you can, including some physical activity every day, balanced by setting aside time for rest during each day

During chemotherapy treatment

Chemotherapy treatment uses anti-cancer drugs to destroy cancer cells. Rehabilitation support during chemotherapy can help you remain as active as possible. Here are some things to consider:

- Talk to your physiotherapist about exercises that you can do in bed, sitting in a chair, or ways in which you can maintain as active a lifestyle as possible throughout the chemotherapy. This will help to reduce the side-effects of the treatment and to help you stay as well as possible
- Ask the occupational therapist for advice on aids and adaptations which can help make you more independent and can also help you manage the tiredness and anxiety which chemotherapy often causes
- Talk to a dietician about maintaining a healthy diet and any appropriate nutritional support you may need. This can help if you feel sick or your taste has changed

After treatment

Being physically active after cancer treatment is a positive step in helping you to recover. It helps you to manage the side-effects of the treatment and also lowers your risk of getting other health problems.

To save you from travelling long distances to the hospital, you can ask to be referred to local rehabilitation services for continued support.

Rehabilitation isn't always short-term and many patients benefit from on-going rehabilitation, even years after their treatment has finished. Talk to your medical team during your follow-up appointments if you feel that you need further support.

Rehabilitation

How do I get referred to these services?

If you feel you would benefit from any of the rehabilitation services listed in this factsheet, speak to your sarcoma clinical nurse specialist or a member of your medical team and ask them to make a referral 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.

Alternatively, if you are not seeing your hospital medical team regularly, it may be easier to speak to your GP who can make a referral to a local service.

Learn more about rehabilitation on our website sarcoma.org.uk/rehabilitation

Further information

Macmillan Cancer Support has a selection of videos on their website explaining the benefits of being physically active both during and after treatment.

View them here: www.macmillan.org.uk/cancerinformation/livingwithandaftercancer
or telephone 0808 808 0000

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Sarcoma UK is the main charity in the UK dealing with all types of sarcoma. Sarcoma UK aims to achieve the best possible standard of care for patients with sarcoma through:

- Funding scientific and medical research into causes and treatments
- Delivering support and information services
- Raising awareness and improving understanding of sarcoma amongst the public, healthcare professionals and policy makers
- Campaigning on behalf of sarcoma patients for improved treatment and care

This factsheet 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 factsheet 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 factsheet 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.



The bone & soft tissue cancer charity



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