

Lymphoedema and sarcoma

Signs and symptoms, prevention and self-management techniques

A Sarcoma UK Factsheet
produced by
the information
and support team

Some treatments for sarcoma can leave you at risk of developing lymphoedema. Learn more about the signs and symptoms, how it can be prevented and the support available to you.



Lymphoedema and sarcoma

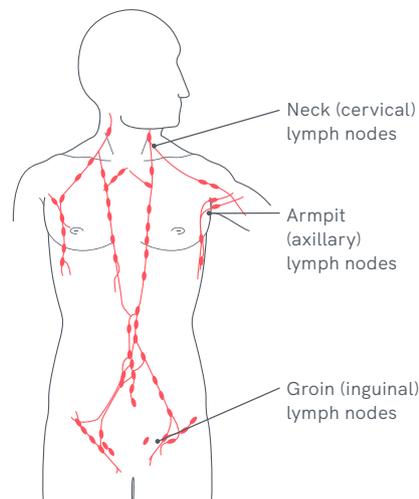
Lymphoedema is a swelling caused by a build-up of fluid in the tissues under the skin. Some treatments for sarcoma, such as radiotherapy and surgery, can damage the lymphatic system. This can cause lymphoedema. This factsheet explains:

- About lymphoedema
- Signs and symptoms
- How to reduce your risk of developing lymphoedema
- Treatment options available



The lymphatic system

The lymphatic system is an important part of the body's immune system as it helps protect us from infection and disease. It is made up of a network of lymphatic vessels which carry a clear fluid called lymph.



The lymphatic system:

- drains excess fluid from body tissues into the blood circulation
- contains white blood cells called lymphocytes. These are carried in the lymph fluid and fight infection
- gets rid of waste products produced by cells



What is lymphoedema?

Lymphoedema is a collection of fluid under the skin. It occurs when the lymph system is damaged, blocked or absent. It can affect any part of the body but is most commonly seen in an arm or a leg.



Lymphoedema and sarcoma treatment

People who have had some treatments for sarcoma could be at risk of developing lymphoedema. This is because some treatments for sarcoma can damage the lymphatic system. You may be at risk of developing lymphoedema if you have had:

- Your lymph nodes removed as part of your surgery
- Radiotherapy to an area of the body where lymph vessels and lymph nodes are located



Signs and symptoms of lymphoedema

If you are at risk of developing lymphoedema it is important to look out for the signs and symptoms. Noticing symptoms early means you can get treated as quickly as possible to reduce the chance of complications.

The most common symptom of lymphoedema is a swelling in the arm or leg caused by a build-up of fluid under the skin. Other symptoms that can occur in the part of the body affected include:

- A feeling of heaviness or tightness
- Restricted range of movement
- Aching or discomfort
- Recurring infections
- Hardening and thickening of the skin called fibrosis

Lymphoedema does not appear directly after treatment so you may not develop symptoms for several weeks, months or even years after your treatment for sarcoma.

It is normal to have swelling following surgery or radiotherapy as this is part of the healing process. However, if your swelling has not gone down within 6-8 weeks speak to your sarcoma CNS for advice.



Prevention

Not everyone who has had treatment for sarcoma will develop lymphoedema. However, it is important to know if you are at risk so you can reduce your chances of developing the condition.

There are a number of ways you can do this.

Look after your skin

Looking after your skin in an at-risk area of the body can reduce the risk of inflammation and infection.

- Keep your skin clean and moisturise with a gentle moisturiser. Try to avoid perfumed lotion as they can dry the skin
- Avoid the midday sun, cover up and use sunscreen to avoid getting sunburnt
- Avoid, where possible, having an injection, such as a flu jab or holiday vaccination, in the area at risk of developing lymphoedema
- Avoid having blood taken from the area at risk
- Avoid getting a tattoo in any area at risk

- Avoid a blood pressure cuff being applied to the area at risk, which can cause skin trauma
- Use insect repellent to avoid insect bites which can cause skin trauma and are an infection risk
- Avoiding cuts and scratches to the skin where possible to reduce the chances of infection which can cause lymphoedema
- Cleanse thoroughly and use antiseptic cream on any cuts and scratches to reduce the chance of infection

Look out for risks of infection

Skin infections can damage your lymphatic system and cause lymphoedema in an area of the body that is at risk.

Signs of possible infection in an area at risk of lymphoedema can include:

- swelling and redness
- skin feeling hot
- discomfort and pain
- flu-like symptoms

If you have an infection in an area at risk of lymphoedema it is important to get treated quickly so that it does not damage the lymphatic system. Your GP can prescribe you with antibiotics to treat the infection.

Keep active and exercise

Keeping active during and after sarcoma treatment can help in several ways. It is important to seek individual advice from a healthcare professional who understands your medical condition.

Taking this advice into consideration, safe and effective exercise will encourage movement of lymph fluid through the lymphatic system. Muscle movements enhance lymph flow, reducing the risk of lymph fluid building up under the skin.

Other benefits to keeping active include:

- Reducing tiredness, stress and anxiety
- Help keep a healthy weight
- Enhance quality of life
- Keep to a healthy weight

If you are overweight it can increase your risk of developing lymphoedema. Your GP, or sarcoma clinical nurse specialist can give you advice on how to maintain a balanced and healthy diet.



What do I do if I show signs of lymphoedema?

If you do develop signs of lymphoedema you should get specialist advice as soon as possible. You can speak to your sarcoma clinical nurse specialist who will discuss your new symptoms with you. It is important to rule out causes for your symptoms other than lymphoedema, such as a recurrence of your sarcoma. If you do not see your sarcoma clinical nurse specialist regularly your GP can help you get specialist advice.



Lymphoedema clinics

If it is appropriate, you will be referred to your local lymphoedema clinic. A lymphoedema specialist will undertake a thorough assessment in order to find out the cause, extent and stage of swelling. They will also ask you for details on how the swelling affects you on a personal level and daily basis. The lymphoedema specialist can then discuss treatment options with you.



What treatment is available?

The causes of lymphoedema are often irreversible and there is unfortunately no cure for lymphoedema at present. Treatment tends to focus on reducing the symptoms of lymphoedema to benefit your quality of life.

Self-management techniques

If you have mild to moderate lymphoedema affecting the arm or leg you will be given some self-care techniques to manage your condition.

Daily skin care

To keep the skin and underlying tissues in good condition and to reduce the risk of infection. See also the Look after your skin section of this factsheet.

Information on how to recognise cellulitis

Cellulitis is a bacterial infection of the deeper layers of the skin and the underlying tissues. The affected area will show signs of infection and the skin may appear, red, hot or swollen. There may be pain or tenderness. **If you think you have cellulitis you should seek medical advice as soon as possible as treatment requires antibiotics.**

Advice on staying active and maintain a healthy weight

See the Keep active and exercise and Keep to a healthy weight sections of this factsheet.

Compression garments

It may be recommended that you wear a lymphoedema compression garment. Providing external support, this aims to encourage movement of lymph fluid through the lymphatic system. This can be influenced further when combined with activity. Wearing a compression garment can help control swelling and reduce symptoms of aching and heaviness.

Your lymphoedema therapist can help you find the right style, pressure and size of garment for you. They can also organise a prescription for compression garments through your GP.

Simple Lymphatic Drainage (SLD)

Your lymphoedema specialist may teach you a massage technique to try yourself called simple lymphatic drainage (SLD). SLD is a sequence of simple hand movements which are designed to encourage movement of lymph fluid through the body. This can soften the affected tissues and reduce swelling. You can practice these techniques at home.

Lymphoedema is a long-term condition and therefore it is important to undertake these self-care techniques on a daily basis in order to reduce the risk of complications. It takes time and effort to effectively control lymphoedema. However, if you continue with your treatment plan, your symptoms may eventually become less noticeable.

Treatment for severe swelling

If you have swelling affecting the 'midline' of the body, or if your swelling has become more severe you may be recommended to have a course of treatment aimed at reducing your symptoms. The 'midline' includes the head and neck region, the 'trunk' or 'torso' and the genital region. This treatment may last 2-4 weeks and is called Decongestive Lymphoedema Therapy or Complete Decongestive Therapy.

You will be offered a combined package of treatments including bandaging and lymph drainage techniques. There are different opinions on which bandaging and lymph drainage technique is most effective. Your lymphoedema specialist can advise you on what treatments are appropriate for you.

The Lymphoedema Support Network have a range of factsheets on the different treatments available for lymphoedema.

Contact them for further information on new innovative treatments for lymphoedema.

020 7351 4480
www.lymphoedema.org



Emotional impact

It can be difficult to come to terms with having a long-term chronic condition such as lymphoedema. Lymphoedema can affect the way you look and have an impact on your quality of life which can be emotionally challenging. Talking through your feelings with family and friends can help. You can also speak to your sarcoma clinical nurse specialist or a counsellor for professional advice and support.

If you have been feeling particularly down or feeling anxious please speak to your GP. They can help you access the support you need.

Lymphoedema Support Network

The UK's national support organisation for people affected by lymphoedema. They provide support and information and promote a network of support groups.

020 7351 4480
www.lymphoedema.org

Talking to us



0808 801 0401



supportline@sarcoma.org.uk

Our Support Line offers practical and emotional support and advice to anyone affected by sarcoma.

- Our support line is independent & confidential.
- We believe no question is a silly question.
- We lend a listening ear.

We can point you in the right direction.