

Lymphoedema



Information for patients

Sheffield Vascular Institute



PROUD TO MAKE A DIFFERENCE

SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST



You have been diagnosed as having lymphoedema. This leaflet explains more about lymphoedema and answers some of the most frequently asked questions. If, after reading it, you have any more questions or concerns, you should write them down and discuss them at your next appointment.

Where will my hospital appointments take place?

Your appointments will usually be at the Sheffield Vascular Institute at the Northern General Hospital. We also run local outpatients clinics at the Royal Hallamshire, Rotherham and Barnsley District hospitals.

The Sheffield Vascular Institute is one of the largest vascular centres in Europe. We specialise in the treatment of all circulatory conditions affecting the arteries, veins and lymphatics. If you wish to find out more about the Sheffield Vascular Institute then look under the Guide to Services on the Sheffield Teaching Hospitals NHS Foundation Trust website: www.sth.nhs.uk

What is lymphoedema?

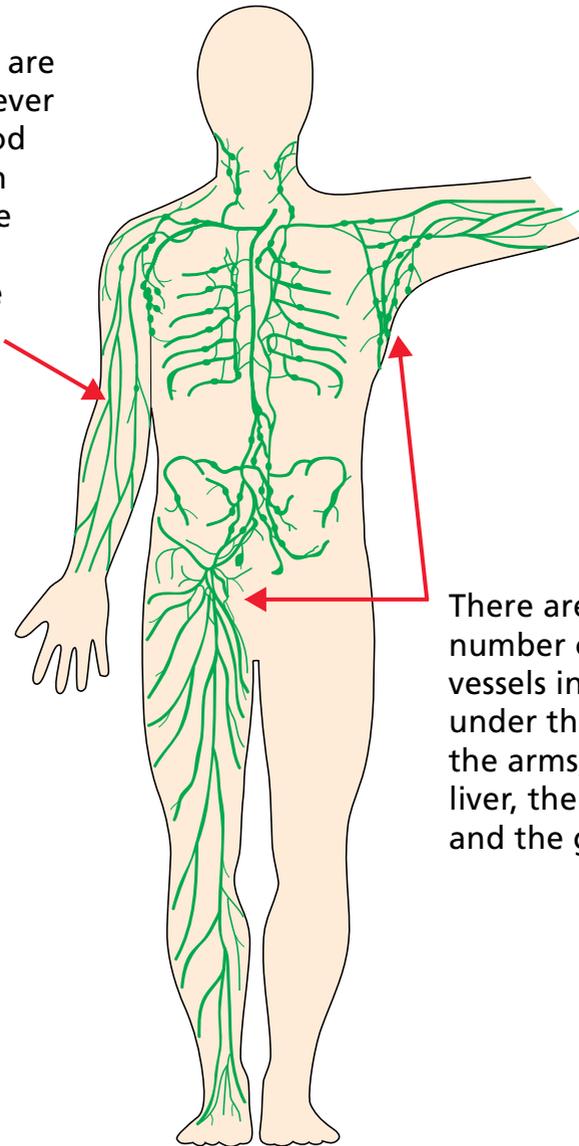
Lymphoedema is an abnormal swelling, due to the build-up of a fluid (**lymph**) in the arm or leg. It can occur in any part of the body but is most commonly seen in an arm or leg. The lymph fluid is made up of protein and waste materials from the body's tissues.

The **lymphatic system** is a network of tiny vessels underneath the skin, which form part of the body's immune system. They help to cleanse the body's tissues, and drain away this clear fluid called lymph.

Lymphoedema occurs when this lymph is not being drained away correctly and so it builds up within the tissues causing swelling or oedema.

To start with, the swelling is often noticeable at the end of the day, but goes down during the night. However, with time, the condition can get worse and the swelling becomes permanent.

Lymph vessels are present wherever there are blood vessels. Lymph vessels remove about 10% of fluid from the tissues of the body.



There are a large number of lymph vessels in the neck, under the jaw, under the arms, around the liver, the intestines and the groin.

What causes lymphoedema?

The causes of lymphoedema can be placed into two categories: primary or secondary lymphoedema.

- **Primary lymphoedema** occurs when there are not enough lymphatic vessels or when the lymphatic vessels do not drain properly. This is usually determined from birth (congenital lymphoedema) but can occur at any stage in life without an obvious cause, but particularly during adolescence (lymphoedema praecox or Milroy's disease). The more severe forms of lymphoedema occur earlier in life.
- **Secondary lymphoedema** occurs when there has been damage to the lymphatic system due to a variety of reasons. The damage may have been caused by surgery or by radiotherapy for the treatment of cancer. Sometimes this is unavoidable if the cancer is to be cured. Accidental injury or infection of the lymphatic vessels may also cause lymphoedema. Reduced mobility or paralysis can also be a cause, simply because exercise and mobility are an important part of how the lymph system drains properly.

Unfortunately the causes of lymphoedema are not reversible and there is no known cure. Good management of lymphoedema can help to minimise the effects of the swelling and prevent it from worsening.

What effects does lymphoedema have?

If left untreated the swelling of the leg can become permanent. In addition to the uncomfortable and unsightly swelling, lymphoedema can cause other problems, especially if not kept under control. Typically the skin becomes thicker and may develop folds and warts. There is an increased risk of infection under the skin (cellulitis) and repeated attacks of cellulitis lead to more damage to the lymphatic vessels. Cellulitis often causes 'flu-like' symptoms, a rash, pain and increased swelling. Prompt administration of antibiotics is essential, and for repeated attacks long

term antibiotics are sometimes needed. Lymphatic fluid can also leak through the skin and leg ulcers can occur. Uncontrolled lymphoedema can also cause problems with mobility due to the size and weight of the legs.

What other conditions cause leg swelling?

Lymphoedema is not the only cause of leg swelling. Swelling also occurs due to problems with drainage through the veins, either due to a blockage of the veins, faulty valves or high pressure in the veins perhaps due to poor heart function. Lipoedema is a form of leg swelling that affects both of the legs, but does not affect the feet. It is thought to occur when there is an abnormal build-up of fat cells in the legs. This condition usually affects females and is usually first noticed during puberty or the menopause. Often this condition can be mixed up with lymphoedema as the symptoms are similar, and some people have a combination of both problems.

Will I need any tests?

Other conditions can often be distinguished from lymphoedema by clinical examination. However, sometimes specialist investigations such as a venous duplex (an ultrasound examining blood vessels and blood flow) or lymphatic scintigram (which provides images of the lymphatic system) are required.

What is the treatment?

Lymphoedema cannot be cured but it can usually be controlled so that the complications do not occur later. The main treatment is skin care, prevention (and where necessary treatment) of cellulitis, external support, elevation and drainage of the lymphatic vessels. Exercise and weight loss (if you are overweight) are an important part of controlling lymphoedema. The ongoing care of lymphoedema is important, and therefore you (or your carer) need to incorporate good leg care into your

daily routine. This will help to prevent the swelling in your leg getting worse and will also help to prevent complications.

Skin care - Healthy skin is soft and supple. In lymphoedema the skin may become thickened and rough, and the site of possible infection. Wash your legs daily and carefully dry them. At least daily, use a good quality moisturiser that suits you and that your health professional has recommended. Avoid scratching, burning or injuring your skin and especially take care when cutting your nails. Look out for signs of infection particularly fungal infections between your toes or in any skin folds.

Treatment of cellulitis - Episodes of cellulitis can usually be treated at home with leg elevation and antibiotics. Occasionally hospital admission is required. Some patients with regular attacks of cellulitis keep antibiotics at home to start immediately when they experience the familiar symptoms of cellulitis. Occasionally we recommend long term antibiotics. It is important to look out for signs of cellulitis (page 5) and see your GP urgently if you think you have cellulitis.

Compression - External support in the form of compression bandages or stockings is useful to control and reduce the swelling of lymphoedema. Bandages may be required at first but most patients will be able to wear compression stockings long term. These stockings need to be specially fitted and are much stronger than ordinary "support tights". For lymphoedema, the usual strength of stocking used is class II but sometimes a stronger class III is required.

Elevation of the limb - Whenever the leg is elevated, fluid will tend to drain out of it. Put your legs up whenever you can and as high as you are able - the arm of the sofa is good. Elevate the foot end of your bed so that your feet are a little higher than your head.

Lymphatic drainage or massage - This is a massage technique that is in the first instance carried out by a specialist nurse or physiotherapist, but can often later be taught to patients or their relatives. It is designed to encourage the drainage of lymph from the affected area, however, not everyone is suitable for this type of treatment.

Exercise - An exercise program is useful in lymphoedema. It should consist mainly of gentle joint mobilisation rather than vigorous exercise. Swimming is a good form of exercise for patients with lymphoedema.

What about drug treatment or surgery?

Other than antibiotics for cellulitis, drug treatment is not thought to be useful for lymphoedema. Some drugs, such as diuretics, may in fact be harmful if prescribed for lymphoedema. If you have any concerns please discuss this with your specialist or GP.

Many operations have tried to cure lymphoedema, but none have been successful. Surgery to reduce the size of the leg may be suggested if the leg remains very swollen, despite compression therapy.

Contact numbers

Vascular Secretary

- **0114 226 9412**

Vascular Nurse Specialist

- **0114 226 9311**
- **0114 271 4688**

What if I need any more information?

You can contact the following organisations:

The Lymphoedema Support Network
St Luke's Crypt
Sydney Street
London SW3 6NH

- **020 7351 4480** (Information and support)
- **www.lymphoedema.org/lsn**

British Lymphology Society (BLS)
9-11 Oldbury Road
Cheltenham
Gloucestershire GL51 0HH

- **01242 695077**
- www.thebls.com



**Sheffield
Hospitals
Charity**

To help support your local hospitals visit
sheffieldhospitalscharity.org.uk

Registered Charity No. 1165762



Yes I donate
ORGAN DONATION

Alternative formats can be available on request.
Please email: **sth.alternativeformats@nhs.net**

© **Sheffield Teaching Hospitals NHS Foundation Trust 2021**

Re-use of all or any part of this document is governed by copyright and the "Re-use of Public Sector Information Regulations 2005" SI 2005 No.1515. Information on re-use can be obtained from the Information Governance Department, Sheffield Teaching Hospitals.
Email sth.infogov@nhs.net