

Lymphoedema information (page 1 of 4)

Please read this along with advice given by your nurses and doctors.

What is lymphoedema?

Lymphoedema is swelling of one or more body parts due to abnormal accumulation of protein-rich fluid in the tissues. It can affect any part of the body but is most commonly seen in an arm or a leg. Although thought to be relatively uncommon, a recent study has estimated that at least 100,000 people in the UK may be affected by this condition.

Although lymphoedema is a long term (chronic) condition, with the right information, support and treatment there is much that can be done to improve both swelling and other symptoms.

The lymphatic system

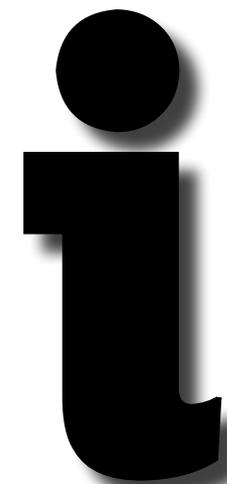
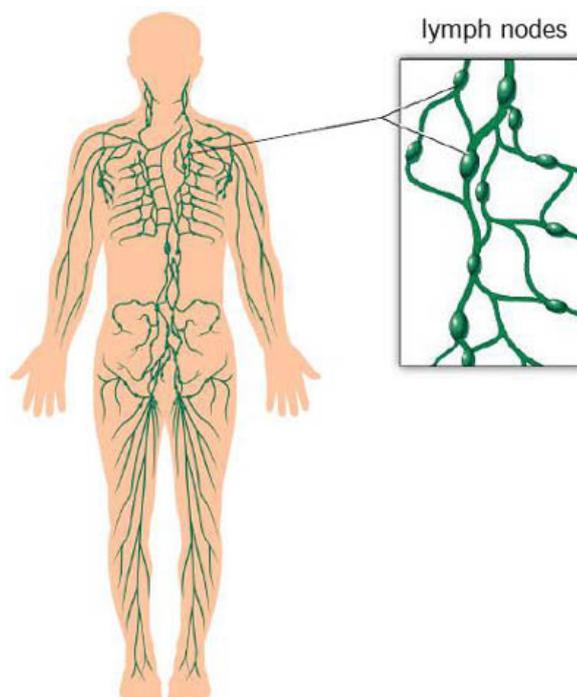
The lymphatics form part of your immune system helping to deal with infection, and they are responsible for cleansing your tissues and maintaining a balance of fluids in your body.

It can be likened to a waste disposal system, taking tissue fluid, bacteria, proteins and waste products away from the tissues around skin, fat, muscle and bone.

Once inside the lymphatic vessels (which initially are barely visible, just under the surface of the skin) the tissue fluid becomes known as 'lymph' and it is then transported in one direction by increasingly

larger and deeper lymphatic vessels. Movement of lymph depends on muscle movement (exercise) and the contraction of the vessels themselves. Gentle massage known as manual lymphatic drainage and deep breathing can also help to move the lymph more effectively.

Lymph passes through lymph nodes, or glands, located in the neck, armpits and groins where the lymph is filtered and cleansed, so that the waste matter and harmful cells can be identified and removed by the body's defence system. The lymph then drains back into the large veins



If you need your information in another language or medium (audio, large print, etc) please contact Customer Care on 0800 374 208 or send an email to: customer care@salisbury.nhs.uk

You are entitled to a copy of any letter we write about you. Please ask if you want one when you come to the hospital.

Please complete The Friends & Family Test to tell us about your experience at: www.salisbury.nhs.uk/FriendsFamily or download our App from the Apple App store or Google Play Store.

The evidence used in the preparation of this leaflet is available on request. Please email: patient.information@salisbury.nhs.uk if you would like a reference list.

Author: Ruth Boyes
Role: Clinical Nurse Specialist
Date written: July 2013
Last revised: April 2017
Review date: April 2020
Version: 1.1
Code: PI1016

Vascular & Diabetes Unit
Tel: 01722 429210

in the neck. From here it goes back to the heart and is eventually removed from the body as urine through the kidneys.

When the lymphatic system fails to work properly the fluid in the tissues builds up (as when a river is dammed and flooding occurs). Swelling occurs when the amount of fluid in an area is greater than the ability of the lymphatic system to transport it away.

What causes lymphoedema?

In primary lymphoedema the lymphatic system does not develop properly; in these cases there is often a family history of the condition. It may develop without any obvious cause at different stages in life, but most often starts in adolescence.

Secondary lymphoedema is the result of some problem outside the lymphatic system that prevents it working properly. Examples of secondary lymphoedema are:

- **surgery** - particularly when lymph nodes are removed after treatment for cancer.
- **radiotherapy** - this kills cancer/tumour cells but it can also cause scar tissue that interrupts the normal flow of lymph in the lymphatic system.
- **accidental trauma, injury or infection** that may damage the lymph vessels and, therefore reduces drainage of lymph.
- **reduced mobility or paralysis** - muscle contractions during activity and exercise are important to help the lymph to move.
- **venous insufficiency** (varicose veins or problems after deep vein thrombosis). This results in the lymph system becoming overloaded and unable to function effectively.
- **cancer** may also result in a blockage of the lymphatic system.
- **obesity** - the combination of reduced mobility and abdominal pressure can cause the lymphatic system to be overloaded.

Unfortunately, most of the underlying causes of lymphoedema are irreversible and there is currently no known cure. However, the right treatment can do much to reduce the swelling and keep it to a minimum and improve the quality of life.

The aims of treatment are to maintain comfort, promote self-care, prevent the condition progressing and prevent infection.

What can be done to help?

Firstly, it is essential that lymphoedema is correctly diagnosed and appropriately assessed. Unfortunately, there is still a major lack of medical knowledge and expertise and some people are still told 'there is nothing that can be done to help'.

However, the British Lymphology Society (LSN) has a directory of services, which will give you your nearest specialist centre (the lymphoedema practitioner has a copy of this); they have also produced a document that sets out minimum standards of care. If you are experiencing difficulties obtaining help ensure your GP is given a copy.

Assessment, carried out by specially trained nurses and physiotherapists, will determine the

cause of the swelling, as well as working out the overall size and extent of the swelling which may affect the type of treatment you are offered.

Generally, there are four components of care that will be recommended for people with mild to moderate swelling of their limbs:

- **skin care to keep the skin and tissues in good condition** and to prevent or reduce the risk of infection. For more information see the LSN 'Skin Care' fact sheet.
- **external support or compression** in the form of elastic compression garments to help prevent the swelling from building up in the limb.
- **a programme of exercise and movement** to try and maximise lymph drainage without over exertion (this would cause the swelling to worsen). For more information on exercise see the LSN 'Recreational Exercise' fact sheet.
- **simple lymphatic drainage** - a gentle massage technique that is based on the principles of manual lymphatic drainage (see below). It involves the use of simple hand movements to try and move the swelling out of the affected area. It is designed to be carried out by patients themselves or with the help of their relatives or carers.

Reassessment and monitoring of progress is essential to ensure good results as is a high level of motivation and compliance by patients themselves.

For people with a more severe swelling additional treatments may be recommended, within a more intensive treatment programme called decongestive lymphatic therapy (DLT) or combined decongestive therapy. This intensive treatment may last for 2 - 4 weeks and combines a package of daily treatments. These may include some of the above, plus one or more of the following:

- manual lymphatic drainage - a specialised form of massage carried out by a trained therapist to move the skin in specific directions based on the underlying anatomy and physiology of the lymphatic system.
- multi-layer lymphoedema bandaging - a multi-layer system of bandages provides a rigid casing for the muscles to work against which helps to improve the shape and size of severe swelling.
- intermittent sequential pneumatic compression therapy - despite this type of therapy being available for numerous years there is no real proof that it works. Caution should be taken when using these machines - they should only be used under the supervision of a lymphoedema practitioner.
- drug therapy - although research is still ongoing, drug therapy for pure lymphoedema is very limited. However, there are certain situations when some drugs will be of benefit - your therapist will be able to advise you.
- surgery - traditional de-bulking operations rarely prove beneficial for lymphoedema, though there are certain situations where it may prove essential e.g. for eyelid or genital swelling. If required, surgery should only be performed by surgeons who have experience with lymphoedema and the lymphatic system.

For more information see the LSN 'Manual Lymphatic Drainage Therapy' fact sheet.

Until relatively recently there were limited options open to people who developed lymphoedema - many were told they would have to live with this often distressing condition. However, with the committed efforts of many health care professionals, effective treatments have become much more widely available. With the continued dedication and enthusiasm of such health care professionals, and the campaigning to raise awareness of the condition by the Lymphoedema Support Network, more and more people affected by lymphoedema will be able to access appropriate and successful treatments.

With appropriate information, and the help and support of a lymphoedema practitioner, there is much that patients can do to help themselves in the management and control of their condition.

For further information please go to:

Lymphoedema Support Network

<http://lymphoedema.org/>