

# What is Lymphoedema?

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## Introduction

Lymphoedema is a swelling that develops as a result of an impaired lymphatic system. This may be as a result of the lymphatic system not developing properly, or through damage or trauma (see section on types of lymphoedema). 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. In order to understand how lymphoedema occurs, it is important to have an understanding of the lymphatic system in general - what it is and how it works.

## The Lymphatic System

The lymphatics form part of your immune system, helping to deal with infection at a local level but just as importantly, 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 (MLD) and deep breathing can also help to move the lymph more effectively.

At some point in its journey, lymph will pass through a lymph node, or gland.

Clusters of these nodes are found in the neck, armpits and groins. It is here that 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.

Having passed through these nodes, lymph finally drains back into the large veins of the body at a point just behind the collarbone, on each side of the neck. From here it goes back to the heart and is eventually removed from the body as urine through the kidneys.

## How Does Lymphoedema Occur?

If, for whatever reason, the lymphatic system is not working correctly, or the vessels are not draining adequately, 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 capacity of the lymphatic system to transport it away. Lymphoedema can, therefore, be defined as 'an abnormal accumulation of protein rich fluid in the tissues'.

## Types of Lymphoedema

Lymphoedema can be described as primary or secondary.

**Primary Lymphoedema** is usually determined from birth and arises due to some failure of the lymphatic system itself - usually with the underdevelopment of the lymphatic system. It may develop without any obvious cause at different stages in life, but particularly in adolescence.

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

- Surgery - particularly when lymph nodes are removed after treatment for cancer: breast, prostate, gynaecological, head or neck, sarcoma or melanoma.
- 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/paralysis - muscle contractions (during activity/exercise) are important to help the lymph to move.
- Problems with veins not working very well (varicose veins/after deep vein thrombosis) - often known as venous insufficiency. This results in the lymph system becoming overloaded and unable to function effectively.
- Cancer itself may also result in a blockage of the lymphatic system.

Unfortunately, most of the underlying causes of lymphoedema are irreversible and as such, there is currently no known cure - however, appropriate treatment can be implemented to reduce the swelling and keep it to a minimum. (See section on 'what can be done to help'). This medical (conservative) treatment can in most cases, improve quality of life dramatically.

### **How Does Lymphoedema Progress?**

Initially, lymphoedema may be very slight and not noticeable all the time. It may be intermittent - and at this stage it is quite common to notice more problems as the day goes on. For example, the swelling may be minimal on waking - but become larger as the day progresses - especially in warm weather. It is often possible to use simple measures to resolve the swelling at this stage so treatment should always be started as soon as possible.

If left untreated, the swelling over time becomes more permanent; it doesn't subside overnight and the area will begin to feel increasingly hard and solid. This is due to the build up of proteins as well as fluid in the tissues.

### **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 has a comprehensive [Directory of Services](#), which will highlight the nearest specialist centre to you (the LSN 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 (usually carried out by specially trained nurses and physiotherapists) will ascertain the actual cause of the swelling, as well as determining the overall size and extent of the swelling, which may alter 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/reduce the risk of infection. For more information see the LSN 'Skin Care' fact sheet.

- **External Support/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 (SLD)** - a gentle massage technique that is based on the principles of Manual Lymphatic Drainage (MLD) (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 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 the patient 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 (CDT). This intensive treatment may last for a period of 2 - 4 weeks and combines a package of treatments on a daily basis. These may include some of the above, plus one or more of the following:

- **Manual Lymphatic Drainage (MLD)** - 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. For more information see the LSN 'Manual Lymphatic Drainage Therapy' fact sheet.
- **Multi-Layer Lymphoedema Bandaging (MLLB)** - 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 of effectiveness. Caution should be taken when using these machines - and 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.

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 (HCP's) - effective treatments have become much more widely available. With the continued dedication and enthusiasm of such HCP's, and the ceaseless 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 and the nihilistic attitude once held will become a thing of the past.

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.

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March 2004