LYMPHOEDEMA

What are the aims of this leaflet?

This leaflet has been written to help you understand more about Lymphoedema. It tells you what it is, what causes it, what can be done about it, and where you can find out more about it.

What is lymphoedema?

Lymphoedema is a long-term swelling that develops because of a fault within the lymphatic drainage system. This may be as a result of the lymphatic system not developing properly, or because it has been damaged.

The lymphatic system is a network of narrow tubes that drain fluid from all areas of the body. It forms part of the circulatory and immune systems. It has several functions, including 1) maintenance of the correct levels of fluid by returning lymphatic fluid from the tissue spaces to the blood, 2) maintaining immune function which helps the body fight infections. The lymphatic system also helps stopping the spread of cancer and controlling diseases caused by inflammation.

When the lymphatic system fails, for whatever reason, there will be complications with fluid balance which results in swelling, and also with increased risk of skin infections. Lymphoedema usually affects the limbs but can affect any part of the body, depending on the underlying cause. Although thought to be relatively uncommon, recent research suggests about half a million people in the UK are living with lymphoedema.

What causes lymphoedema?

Lymphoedema can be either “primary” or “secondary”.

Primary lymphoedema is a rare condition that is often inherited through the genes. The lymphatic system fails to develop normally, causing swelling of

the affected region. The lymphoedema swelling may be present at birth or may develop later in life, often after puberty. There are different types of primary lymphoedema and the underlying genetic cause can be identified in about 25% of people. Dedicated primary lymphoedema clinics are available to help the local lymphoedema clinics with the investigation and diagnosis of suspected primary lymphoedema.

Secondary lymphoedema is a more common problem. It happens when a person with a previously healthy lymphatic system develops a problem or illness that damages it and prevents it from working properly.

Examples of secondary lymphoedema include:

Cancer treatment: Lymph nodes are often removed during treatment for cancer and this causes disruption to the normal drainage of lymph. It may occur in treatment for breast, prostate, gynaecological, head or neck cancer, sarcoma or melanoma. Lymphoedema may develop in up to 20% of people undergoing lymph node surgery as part of their cancer treatment.
Infection: Infections, such as cellulitis of the leg, may damage the lymph vessels and therefore, reduce drainage of lymph.
Severe inflammatory problems: Long-term inflammation of the skin can rarely lead to damage of the lymphatic vessels in the affected area. Lymphoedema can therefore affect some people with facial acne/rosacea; genital hidradenitis suppurativa; psoriasis and dermatitis.
Reduced mobility/paralysis: Our body needs muscle contractions during activity/exercise to help the lymph to move around our body. Therefore, immobility will eventually cause lower limb swelling.
Vein problems (e.g. varicose veins, after deep vein thrombosis): Venous problems, also called venous insufficiency, results in the lymph system becoming overloaded and unable to function effectively.
Obesity: this can also cause lymphoedema or worsen the swelling problems.

What are the symptoms of lymphoedema?

In the early phase of lymphoedema it may just present with slight swelling that comes and goes (intermittent); for example, an ankle, leg or foot. The swelling may disappear overnight but become noticeable at the end of the day or in hot weather. Lymphoedema of the lower leg may sometimes ache and feel heavy, but lymphoedema is very rarely painful. It is often possible to minimise the swelling with simple compression garments this stage, so treatment should be started as soon as possible.

If left untreated, the lymphoedema swelling becomes constant and may worsen; it no longer resolves from overnight elevation in bed and the area will

begin to feel increasingly hard and solid. This is due to the build-up of cells, protein and fat as well as the fluid within the tissues. Over time, the skin will change and become thicker, bumpy and scaly.

Cellulitis:
Lymphoedema increases the risk of developing cellulitis especially if swelling is poorly controlled. Cellulitis is a bacterial infection of the deeper layer of the skin. Symptoms include redness and warmth of the skin. There may be increased swelling and pain at the site of infection. Lethargy and feeling 'flu-like are common but feeling very unwell with a high temperature may occur. Cellulitis can sometimes be difficult to diagnose and blood tests may not be helpful.

Prompt treatment with antibiotics is required. Oral antibiotics need to be given for two weeks in people with lymphoedema, as this can take longer to resolve. For severe infections intravenous antibiotics may be required. Recurrent episodes of cellulitis (2 or more infections per year) may demand a prolonged course of prophylactic antibiotics for 2 years to prevent further infections (www.lymphoedema.org/index.php/cellulitis/cellulitis-in-lymphoedema for guidance).

How is lymphoedema diagnosed?

Lymphoedema is usually diagnosed by the symptoms and clinical signs alone. Occasionally, a specialist doctor will request a lymph scan (lymphoscintigraphy) to confirm the diagnosis. This test uses a special dye (injected in the hand and/or feet) to see how well the lymphatic system is working.

How can lymphoedema be treated?

Unfortunately, there is no cure for lymphoedema at the moment. Management is aimed at controlling swelling through physical treatments designed to stimulate flow through existing or collateral drainage routes. Mild to moderate cases of lymphoedema can be treated with exercise plus fitted compression garments worn on a daily basis. Adjustable Velcro compression wraps can also be used. More severe cases of lymphoedema are treated with intensive compression bandaging over a period of a few weeks to reduce the limb volume before compression garments are fitted for maintenance. Compression in combination with exercise, weight management and good skin care can be very effective. These treatments can be provided by a local lymphoedema therapy clinic for most patients, via a referral from their GP.

Whilst no drugs are currently available to stimulate lymphatic function, several drug trials are in development.

Several surgical techniques have been implemented in recent years in a bid to improve lymphatic drainage or achieve limb volume reduction via liposuction. However, in the absence of robust data to support most surgical techniques, the majority of patients rely on compression therapy to manage their swelling.

Self care (What can I do?)

- If possible, ask your GP for a referral to a lymphoedema clinic in the early stages of developing lymphoedema, instead of waiting until the swelling has become hard and fixed. (The Lymphoedema Support Network holds a comprehensive list of clinics in the UK).
- It is important that you remain active and exercise on a regular basis to stimulate your lymphatic system to work better.
- If you are overweight then it is recommended to lose weight (ideally to a healthy BMI range of 19-25) to improve your lymphatic drainage, as fat attracts fluid and worsens lymphoedema.
- Skin care (e.g. keep the skin clean and moisturised) to keep the skin and tissues in good condition and to prevent/reduce the risk of infection, in particular between the toes..
- Aim to elevate swollen legs when sitting and try to avoid long periods of standing.
- Try not to sleep in arm-chairs or with the leg hanging out of bed as this will lead to accumulation of fluid.

Where can I get more information about Lymphoedema?

Web links to detailed leaflets:

NHS Website
https://www.nhs.uk/conditions/lymphoedema

British Lymphology Society (BLS)
www.thebls.com

Links to patient support groups:

The Lymphoedema Support Network (LSN)
www.lymphoedema.org

For details of source materials used please contact the Clinical Standards Unit (clinicalstandards@bad.org.uk).

This leaflet aims to provide accurate information about the subject and is a consensus of the views held by representatives of the British Association of Dermatologists: individual patient circumstances may differ, which might alter both the advice and course of therapy given to you by your doctor.

This leaflet has been assessed for readability by the British Association of Dermatologists' Patient Information Lay Review Panel

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