What is lymphoedema?

Lymphoedema is a chronic swelling that can affect any part of the body, but is most commonly seen in an arm or a leg. It is a condition that develops when the lymphatic drainage system is unable to work effectively; it has either become damaged, overloaded or its function is impaired. This results in a build-up of fluid and other substances (such as protein) in the tissues. A swelling can develop when the lymph vessels cannot keep up with the extra demands on their drainage capacity.

In the early stages, the swelling may be soft to the touch and may come and go, especially overnight when the limbs are less dependent. Over time, the swelling becomes a more constant feature – normal limb architecture such as tendons, veins and ankles disappear and the limb may start to feel solid and thickened. In these cases the limb can feel heavy, tight and uncomfortable and the skin can become dry.

This fact sheet aims to offer appropriate information and advice to help minimise the possibility of people ‘at risk’ of developing lower limb lymphoedema (LLL).

Who may be at risk of developing LLL?

You could be at risk of developing swelling if you answer yes to any one (or more) of the following questions:

1. Do you have a family member who has a history of swollen legs or feet?
   Primary lymphoedema is a condition that can run in families and can be determined from birth or later in life. It can be hereditary, but not always. It can occur in both males and females and usually affects the legs, though other parts of the body can be involved too (arms, face and genitals). The condition may be present at birth, or soon after, but it can also occur without warning at any age. In the latter, there is often an incident that ‘triggers’ the swelling such as injury or trauma, infection or a change in hormone levels, e.g. puberty or pregnancy. Diagnosis is usually made through careful history and clinical examination, but an investigation known as lymphoscintigraphy can also help to confirm it.

2. Have you had surgery to transplant, move or remove lymph nodes (glands) in your abdomen or groin and/or have you had radiotherapy to your abdomen or groin?
   People, particularly those who have had cancer in the abdomen or pelvic area, prostate, or genital areas, are at risk of developing secondary lymphoedema because this type of treatment may damage/reduce the function of the lymphatic system. There is an increased risk of developing lymphoedema if you have had surgery and radiotherapy in the same area. There may also be a risk of swelling in a limb where lymph nodes at the root of that limb have been removed and transplanted to another area to try and improve lymphoedema (Surgical Lymph Node Transplant).

3. Are your medications affecting your risk of swelling?
   There are certain medications that are known to increase your risk of swelling. We all respond to medication differently, but if you notice new or increased swelling after starting a medication, please discuss with your GP if this is the best medicine for you. Drugs like Amlodipine, used for treating high blood pressure (hypertension) can promote lymphoedema.

4. Do you have scars from burns, radiation or injuries, or have you had surgery in the abdomen, pelvic area or in the legs?
   Any trauma that damages the lymphatic system that is present in, or just under, the skin may increase the risk of developing secondary lymphoedema – because the drainage system has been damaged, the excess fluid that accumulates finds it difficult to drain away.

5. Have you had problems with recurrent cellulitis (erysipelas) or infection in your legs?
   People who have had one or more infections in the legs may have some residual swelling as a result of the lymphatic vessels becoming damaged during the infection. It is very important that anyone who suffers an attack of cellulitis is investigated as to why – and if swelling persists afterwards, that they are referred to a lymphoedema clinic for assessment. Other types of infection such as filariasis (parasitic infection transmitted by mosquitoes in countries such as Africa, India) may also cause lymphoedema.
6. Do you have a chronic skin disorder affecting the lower body/legs or feet?
Long-standing skin disorders such as psoriasis or eczema can eventually lead to the superficial lymphatics becoming damaged or blocked and swelling may then also become problematic.

7. Do you suffer from varicose veins, varicose leg ulcers or have you had a deep vein thrombosis (DVT)? Have you had veins removed from your legs, e.g. stripping of varicose veins or removal of veins for heart bypass surgery?
When the venous system is not working adequately, the veins release more fluid into the legs and the normal transport capacity of the lymph system can become overwhelmed. Over time, this can damage the lymphatics and lymphoedema can develop.

8. Do you suffer from immobility, for whatever reason?
People suffering from any condition that prevents the normal limb function (such as neurological disorders, a stroke, or those weakened by other diseases/injuries) are at risk of leg swelling because the muscles (which normally contract and relax during exercise and movement) are not working as effectively as they should. As a result, the venous and lymphatic systems are not given the impetus to drain as effectively and a dependent (or gravitational) swelling of the lower legs and feet can become a problem. Swelling also becomes increasingly more problematic with age, as mobility decreases.

9. Are you overweight?
Lymphoedema may develop in conjunction with obesity. Being overweight causes stress on the lymphatic system and it can struggle to drain efficiently. The flow of lymph can be blocked when rolls of fat (such as that in the lower abdomen) compress the normal flow in the groin. As weight increases and exercise becomes more difficult, the lymphatic system does not have the impetus to drain because of the lack of muscle movement and swelling may worsen.

10. Do you have lipoedema?
Lipoedema is a bi-lateral (and symmetrical) limb swelling mainly affecting the legs and thighs (the feet are often unaffected) and is thought to occur as a result of an abnormal accumulation of fat cells in the tissues under the skin.
The tissues of the limbs appear loose and ‘floppy’ and are often very tender or painful to touch. Bruising can occur easily and spontaneously (without any apparent cause). Over time, the swelling can obstruct the lymphatic system leading to a mixture of the two conditions – lipo-lymphoedema.

For more information, see the LSN fact Sheet, ‘Lipoedema’.

How to recognise LLL
Symptoms of lymphoedema can develop immediately after the causative event or can appear, without any warning, months or years later and include the following:
- Swelling of the affected limb(s) that usually develops gradually over a period of time. It may be an intermittent swelling initially – obvious one day and not so noticeable the next. Shoes and clothing may suddenly feel too small or tight. It may well reduce overnight when the legs are elevated and is often worse at the end of the day. Sudden onset of swelling generally indicates a more acute cause and may need further urgent attention/assessment.
- Tightness and tension in the limb(s) as the surrounding skin is stretched.
- As the limb increases in size, there is often a feeling of heaviness in the affected area.
- The normal ‘architecture’ of the limb is not so apparent (e.g. tendons/bones/veins are not as prominent).
- The swelling may ‘pit’ in the form of a temporary indentation that appears when pressure is placed on the swollen area.
- Discomfort, or even pain, in the affected area as the swelling interferes with nerve endings.
- Inflammation or infection may become apparent when the swelling may suddenly increase in size and the limb becomes red and painful. Flu-like symptoms may accompany this episode alongside nausea and vomiting. This is called ‘cellulitis’, which is more common in those with lymphoedema. Cellulitis requires immediate medical advice through your GP or out of hours service. See the LSN fact sheet on ‘The Management of Cellulitis’ for further advice.
- The weight of a swollen limb might contribute to aching in the adjacent hip or joints and if the swelling increases, reduced function and mobility may become problematic and posture and balance will become increasingly affected.

How can I reduce the risk of developing LLL?
Avoid infection and injury to the ‘at risk’ area
People who have impaired lymphatic drainage, for whatever reason, should try to avoid any trauma or damage that may cause a break in the skin.
Any skin damage may lead to an increased risk of infection which in turn may trigger lymphoedema. The following advice is therefore recommended:
- Wear long trousers and supportive shoes when out walking.
- Use insect repellents to avoid bites – use 50% DEET if travelling to problematic areas and consider buying outdoor clothing impregnated with DEET as a further deterrent. However, there are other more natural/
organic products available too and though more expensive, do contain less toxic chemicals and are more pleasant to use.

- Wear something on your feet at all times – especially important when outdoors. Use protective footwear on the beach, for example.
- Take care when cutting nails – try to cut the nails straight across to minimise the risk of in-growing toe nails. If you cannot manage this yourself, consider seeing a chiropodist.
- Maintain good foot hygiene – wash and dry thoroughly, especially between the toes. High absorbency foot powder may be used if necessary and cotton socks are preferable.
- Observe for signs of fungal infections, such as athlete’s foot, between the toes or in the nails and treat promptly. Prevention is vital if this is a common problem.
- Take care when shaving – ideally use an electric shaver as wet shaves can easily cut the skin. Be careful of depilatory creams – ensure there is no sensitivity to the product first. Waxing is not recommended, but laser hair removal is perfectly safe.
- If you have specific risks, such as reduced lymph nodes in the groin following surgery, it is helpful to avoid having injections into your legs, abdomen or buttocks whenever possible – carry this information sheet to show to healthcare professionals so that they are aware of your circumstances.
- Acupuncture is not recommended in the ‘at risk’ limb but may be used in other areas of the body.
- Tattoos should also be avoided on affected/’at risk’ area.
- Try to avoid scratches from pets. If a cut or scratch occurs, clean the area, treat with antiseptic, then cover and check every 24 hours for signs of infection.
- Prevent sunburn (or any other burn) – high factor sunscreen is recommended (SPF 30 or above).

Be aware of what is ‘normal’ for you and regularly observe for changes and any signs of infection (redness, pain, warmth, sudden swelling and fever). It is essential to contact your GP immediately if an infection is suspected (antibiotics will be urgently required) – remember, an infection can actually cause lymphoedema, so avoiding trauma and infections are vital. Inflammation of your legs may also be evident at times – and is often confused with infection. Seek medical advice as soon as possible if you are at all unsure.

The LSN has more information about infection and its treatments – as well as the antibiotics that are recommended. See the fact sheets ‘What is Cellulitis?’ and ‘Management of Cellulitis in Lymphoedema’.

Keep your skin in good condition

- Try to keep the skin on your legs and feet spotlessly clean, soft and well moisturised.
- Wash with soapless cleansers that won’t dry out the skin and pat the skin dry thoroughly, especially between the toes and in any creases. Use a hair drier on a low setting, if unable to reach the feet.
- Apply any moisturising cream/lotion (that you like to use) to your legs/feet on a daily basis to keep the skin soft and supple. Avoid highly perfumed creams/lotions and those with lots of additives, if possible, as this may cause skin sensitivity.
- See a podiatrist to treat any corns/calluses, nail and fungal infections to prevent cellulitis developing.

Avoid items of clothing that are too tight or restrictive

Anything that is too tight or restrictive will further impair the lymphatic drainage. You should therefore avoid:

- Wearing socks, stockings or underwear/trousers/skirts that have tight elastic bands.
- High heels or tight straps – wear comfortable and supportive footwear with high tops wherever possible – reserve other footwear for special occasions.

Learn what sort of exercise works for you.

Exercise is very important and will help to stimulate lymphatic drainage and venous return. It will also keep you fit and help maintain a healthy weight. It is best if you start with activities that feel comfortable, gradually building up your strength, stamina and resistance.

- Start with gentle, specific and regular exercise and build up the activity over time.
- Do not overtire the leg(s) at risk. If they start to ache, rest!
- Recommended exercises include brisk walking (Nordic (pole) walking particularly), swimming or water based exercises, light aerobics, cycling, yoga, Pilates and T’ai Chi.
- Gradually build up any programme of vigorous repetitive movements against resistance (particularly those that feel like they are putting a heavy strain on your legs) e.g. in the gym. Too much, too soon, can overwhelm an ‘at risk’ limb.
- Avoid standing/sitting in one position for long periods of time – try to keep moving or perform gentle exercises to keep the muscles working.

Use your legs as a guide to how much you can do

It is better not to exercise in the heat of the day. Whatever exercise you choose, build up the amount you do gradually. Appropriate positioning of your legs whilst at rest will also lessen the likelihood of swelling occurring. Rest with your legs supported and, if possible, elevated so that your legs are higher than your heart (such as reclining on the settee or in bed).

Dealing with heat

- Try to avoid extreme temperature changes when bathing or in sunshine.
- Try to stay in the shade when possible or cover up the ‘at risk’ area (increased temperatures can increase tissue fluid which may have difficulty draining away).
Always wear a high factor sunscreen (SPF 30 or above).

Avoid hot water bottles and heat-producing ointments such as ‘Deep Heat’.

Avoid saunas and hot tubs and cold power jets in spas.

Enhancing general well-being

Try to maintain a healthy weight (BMI) by following a well-balanced, high fibre and low salt diet.

Avoid smoking and limit alcohol where possible.

Drink plenty of water. This will not cause a limb to swell.

Do not avoid protein – although lymphoedema is a high protein oedema, eating too little protein will weaken the connective tissue. Eat easily digested proteins such as chicken, fish and tofu.

Ensure that exercise is fitted into your daily routine.

What to do if you think you have lymphoedema

If you have any symptoms mentioned in this fact sheet, please consult your GP as soon as possible. Your GP may decide to do some investigations prior to a referral to a lymphoedema clinic (where specialists have the skills to manage the swelling), including:

- Blood tests (to check that there is nothing that may be contributing/causing the swelling, such as anaemia, low blood protein levels).
- X-rays, ultrasound examinations, CT or MRI scans (to rule out any obvious cause of the swelling).
- Doppler ultrasound examination to rule out circulatory problems.

The LSN has a comprehensive list of lymphoedema clinics in the UK, so please contact the LSN office if you need more information or advice.

What to expect from a lymphoedema clinic

Lymphoedema clinics are generally run by specially trained nurses, physiotherapists, or occupational therapists and they will usually see you for an assessment appointment prior to the planning of any treatment that may be required.

Treatment is varied according to your needs, but often includes some or all of the following:

- Skin and general health care advice
- Exercise
- Use of compression garments and/or padded bandages
- Intermittent pneumatic compression pumps
- Kinesio taping
- Psychological support
- Self-management strategies

Other treatments used by some clinics may also include:

- Low level laser therapy
- Deep Oscillation therapy or Negative Pressure devices, incorporated with Manual Lymphatic Drainage (MLD).

Most clinics will see you on a regular basis until your swelling is stable and you have a good idea of how to self-manage this long-term condition.

The aim of this fact sheet is to offer appropriate help and advice to all those who may be at particular risk of leg swelling – for whatever reason. It is not aimed to frighten or alarm, but to point out that early intervention is vital to ensure more successful results and prevent reduction of quality of life.

By raising awareness, preventative steps can be taken by everyone who is at risk of developing lymphoedema in the legs.

Please do not ignore the warning signs and symptoms of lymphoedema – seek help as soon as you can. Although lymphoedema cannot be cured, its progression can be halted and the sooner treatment is started, the more effective it can be.

Excellent results can often be achieved through appropriate management and early intervention.

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