

# Patient information

## Information and advice

### What Is Lymphoedema?

Lymphoedema is swelling that develops because of a build-up of fluid in the body's tissues. This happens when the lymphatic system, which normally drains the fluid away, isn't working properly. It can occur in any part of the body, but is most likely to affect an arm or a leg.

Lymphoedema develops when lymph nodes or vessels are damaged or blocked or if the lymph nodes have been removed by surgery. Lymphoedema is caused when lymph fluid cannot pass through the vessels or lymph nodes and the fluid cannot drain away in the usual way. The fluid then builds up between the tissues and causes swelling.

Lymphoedema is a chronic condition that can be treated and maintained but cannot be cured, however the swelling can be reduced in most people, particularly when it's diagnosed early. Specialists in lymphoedema can assess and treat lymphoedema. They can also teach you how to manage it yourself.

### What the service provides

The Lymphoedema Service provides an assessment carried out by one of the specialist nurses or therapists, who have undergone training at specialist level. You are diagnosed on the basis of your medical history and physical examination, which provides confirmation of a diagnosis of lymphoedema, either primary or secondary:

- **Primary:** abnormality of the lymphatics.
- **Secondary:** lymphatic failure as a result of damage to an otherwise normal lymphatic system.

The specialist nurse/therapist may also request specialist investigations if they

deem it appropriate for your care/management. Your assessment will ascertain the actual cause of the swelling and will determine the overall size and extent of your limb. They will then explain your management/treatment.

Once you have been assessed and the most appropriate treatment discussed (which can include compression therapy), you will be invited to a self-management workshop. This is an hour and half long session which will inform you about all the relevant information needed as part of your self-management. We will also teach you your self-lymphatic massage.

## **General advice and guidance**

### **If your arm is affected**

- Wear gloves for washing up or gardening.
- Use oven gloves in the kitchen for hot dishes.
- Use the unaffected hand to remove packages from the freezer.
- Use a thimble for sewing.
- Avoid carrying heavy shopping or bags on the affected arm.
- Avoid carrying heavy shopping or bags on the affected arm
- Do not lift heavy objects: avoid pushing or pulling any heavy loads.
- **Try to use your limb as normally as possible, this aids lymph drainage**

### **If your leg is affected**

- Wear long trousers in the garden: use a knee shield when kneeling.
- Do not go bare-foot around the house, beach, swimming pool or communal showers.
- Use a protected blade or electric shaver.
- Try to avoid standing for long periods or sitting with your feet on the floor.
- Rest your leg outstretched on a stool or on the sofa. Your foot should be level with your bottom and the back of your knee supported.
- Try to use your limb as normal as possible, this aids lymph drainage.

### **If your neck or head is affected**

- Use an electric razor.
- Do not wear tight collars, ties, scarves or necklaces.
- Use products that have been tested beforehand (small test area), or products for sensitive skin.

Please remember to keep hydrated. If dehydrated, the body can retain fluid which can lead to an increase in your swelling. Signs of dehydration are:

- Feeling thirsty.
- Dark yellow or strong smelling urine.
- Feeling dizzy or light headed.
- Feeling tired.
- Dry mouth, lips and eyes.
- Urinating little or less than four times a day.
- Low blood pressure.

### **General advice**

- Take care when cutting or filing your nails: try and see a chiropodist or podiatrist.
- Use insect repellent: make sure pets are free of fleas.
- Always use an electric shaver to remove unwanted hair: depilatory creams can cause irritation and a razor can nick the skin. Use of epilators, electrolysis, waxing and laser can all damage the skin (lasers used under medical supervision of the practitioner will take precautions).
- Adhere to good hygiene and skin care: moisturise daily.

### **Please report any changes to your condition to your nurse or therapist**

- Signs of infection.
- Signs or problems with your circulation.
- Your lymphoedema increasing in volume and shape change.
- Changes in sensation or feeling of the affected area.

### **Useful information and websites**

#### **Lymphoedema Support Network (LSN)**

St Luke's Crypt, Sydney Street, London, SW3 6NH

Telephone: 020 7351 4480 for information and support

Telephone: 020 7351 0990 for administration

e-mail: [adminlsn@lyphoedema.freeserve.co.uk](mailto:adminlsn@lyphoedema.freeserve.co.uk)

Website: [www.lymphoedema.org](http://www.lymphoedema.org)

**British Lymphoedema Society (BLS)**

The Garth House, Rushey Lock, Tadpole Bridge, Buckland Marsh, Nr Farringdon,  
Oxfordshire, SN7 8RF

Telephone: 01452 790178

e-mail: [info@thebls.com](mailto:info@thebls.com) or visit BLS website

**Macmillan Cancer Support**

Telephone: 0808 808 00 00

Monday to Friday 9.00 am – 8.00pm

or visit their website: [www.macmillan.org.uk](http://www.macmillan.org.uk)

*If you would like any information regarding access to the West Suffolk Hospital and its facilities please visit the hospital website [www.wsh.nhs.uk](http://www.wsh.nhs.uk) and click on the link, or visit the disabledgo website:*

*<http://www.disabledgo.com/organisations/west-suffolk-nhs-foundation-trust/main>*

© West Suffolk NHS Foundation Trust