

Lymphoedema

The aim of this information sheet is to help answer some of the questions you may have about lymphoedema. If you have any questions or concerns, please do not hesitate to speak to a doctor or nurse caring for you.

What is lymphoedema?

We all have a small amount of fluid (lymph) in our body tissues. This fluid leaves our blood system to provide water and nourishment to the tissues. Most of this fluid is collected by a system of drainage tubes, similar to blood vessels called the lymphatic system.

Lymphoedema is swelling which is due to a build up of lymph in the limbs if the fluid is not draining out properly. To start with the swelling is often noticeable at the end of the day and goes down at night. However, unless the swelling is treated properly, the fluid becomes fixed in the leg permanently.

What causes lymphoedema?

The most common cause for lymphoedema is that you were born without enough lymphatics but you may not have been aware of this until you noticed some swelling. This type of lymphoedema is called Milroy's Disease. One leg is often worse than the other and sometimes only one leg is affected. In less severe cases the lymphatics may be able to cope initially and only start to fail when you are older. This kind is sometimes called Lymphoedema Tarda.

Are there any other causes?

Lymphoedema can also be caused if the lymphatics of the arm and leg are damaged by surgery or radiotherapy for the treatment of cancer. Sometimes this is unavoidable if the cancer is to be cured.

There are also some rare tropical parasites (Filariasis) that invade and block the lymphatics. However it is extremely rare for this to be the cause of your lymphoedema as these parasites do not live in Great Britain.

What effects can lymphoedema have?

Apart from the uncomfortable and visible swelling, lymphoedema can cause problems, especially if it is not kept under control.

There is an increased risk of infection under the skin (cellulitis) and repeated attacks of cellulitis lead to more lymphatic damage. This vicious circle may eventually lead to severe infections, ulcers and even amputation in extreme cases.

What is the treatment?

Lymphoedema cannot be cured but it can usually be controlled so that complications do not occur later. The main treatments are compression bandages or stockings, elevation of the limb, deep tissue massage, meticulous skin care and external pneumatic compression.

- **Elevation** - whenever the leg is elevated, fluid will tend to drain out of it. Put your legs up whenever you can and as high as you are able – the arm of a sofa is good. Elevate the

end of your bed (six inches or more) so that your feet are a little higher than your head. You can use some old books for this.

- **Compression bandages/stockings** - compression is required to squeeze the fluid out of your legs when you are standing up. Bandages may be required at first, to remove the worst of the swelling, before stockings can be used. These stockings need to be specially fitted and are much stronger than ordinary “support tights”. If the swelling only affects the lower leg, then you can wear a below-knee stocking that is self-supporting like a pop sock. The usual strength of stocking is a class II, but sometimes a stronger class III is required. If you have difficulty putting on your stockings then you can buy a special stocking applicator.
- **Deep Tissue Massage** - safe massage techniques are available for lymphoedema. The two most prevalent types of lymph massage techniques are Lymphatic Drainage Therapy and Manual Lymph Drainage. These techniques use very light pressure in gentle rhythmic motions to increase the flow of lymph fluid out of swollen tissues. Please visit the National Lymphoedema Network Website for recommended treatment centres/professionals: www.lymphnet.org
- **Skin Care** - it is important to take very good care of the skin due to the increased risk of infection with lymphoedema. Never walk around barefoot.
- **External Pneumatic Compression (EPC)** - despite compression stockings, many people find that some swelling accumulates by the end of the day. The EPC device is a pneumatic boot that inflates and deflates to squeeze fluid out of the leg. EPC is normally used in the evening to get rid of any fluid that has built up despite compression stockings. If your doctor thinks you need EPC therapy, a trial of the device will normally be arranged so that you can decide whether it is worth buying one.

What about surgery?

There are no operations that cure lymphoedema. Surgery is usually used as an option once the leg becomes very heavy to reduce the bulk of the leg; these operations are known as a Homan’s Reduction or a Charles Procedure.

How can I help myself?

- Wear your compression stockings every day from morning to night.
- Elevate your legs whenever possible
- Take plenty of exercise and don’t put on weight
- Keep the skin in good condition by using plenty of moisturising cream to prevent dryness.
- Never walk around barefoot.

What can I do to help myself?

Smoking: If you are a smoker the single most important thing you can do to help yourself is to give up smoking. Stopping smoking will also help to protect all of your arteries making it less likely that you will suffer from heart attacks or strokes. Giving up is not easy but there is a smoking cessation service and support groups that can help. Your vascular specialist nurse or GP practice nurse can advise you about these. You can contact the free NHS smoking helpline on 0800 022 4 322 or the Knowledge & Information Centre (KIC) (details below) who will give you details of our support services.

Inactivity: Gentle exercise such as walking and cycling are recommended to help improve your overall level of fitness. Exercise helps your body to produce healthy cholesterol and this helps to protect your arteries against bad cholesterol.

High blood pressure: It is very important that you have your blood pressure checked regularly, at least every six months. If you have been prescribed medications for high blood pressure, you must make sure that you take it according to the instructions given.

Diabetes: If you have diabetes it is important that your blood sugar levels are well controlled.

High blood cholesterol levels (fatty substance in your blood): You should eat a healthy balanced diet and try to reduce any excess weight. It is important to reduce the level of cholesterol in your blood. Your vascular nurse can refer you to a dietician if needed. You may be prescribed medication to help lower your cholesterol level (e.g. a statin) and low-dose aspirin to help prevent blood clots from forming.

Contact us

If you have any questions or concerns before or after you have left hospital, please contact the **vascular specialist nurses on 07825 503902** (Monday to Friday 8am – 4pm).

You can also contact **Luke ward on 020 7188 3566 or Sarah Swift ward on 020 7188 8842** (24 hours) and speak to the ward sister or nurse in charge.

The above contacts can put you in touch with the following vascular consultants should you wish to do so: **Miss Rachel Bell, Mr Stephen Black, Mr Michael Dialynas, Mr Tommaso Donati, Mr Bijan Modarai, Mr Morad Sallam, Mr Mark Tyrell, Mr Hany Zayed, Mr Said Abisi, Mr Sanjay Patel, Miss Beck Sandford, Mr Andrew McIrvine.**

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch using the following contact details.

t: 020 7188 8815 **fax:** 020 7188 5953

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

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