Lymphoedema Patient Information

What is lymphoedema?
Lymphoedema is swelling caused by a build-up of lymph in your limbs. It happens when your body’s lymphatic system (which is part of the circulation system) is not working properly, meaning that excess fluid from your limbs is not draining.
The effects of lymphoedema are an uncomfortable and unsightly swelling, an increased risk of infection under the skin, and further damage to the lymphatics.

Lymphoedema is not life-threatening, but once you have it, it can only be managed, and not cured.

What causes lymphoedema?
Lymph is a clear, protein–rich fluid that contains many white blood cells, which are involved in fighting infection. At times, your body produces excess lymph, for example, when there you have an infection, trauma, or disease, or when muscle cells work hard during strenuous exercise. Normally the body’s lymphatic and venous system can cope with the excess fluid, but if either is damaged, the fluid will build-up in the tissues and thickens, which causes swelling.

Primary lymphoedema is something you are born with, or develops in puberty, or later life. Normally this is because you were born without enough lymphatics. This is called Milroy's disease. One leg is often worse than the other, and sometimes only one leg is affected.

Secondary lymphoedema is caused by an injury or damage to the lymphatic system. Some possible causes of secondary lymphoedema are:

- surgery
- physical accident
- infection
- radiation treatment (for example, for cancer)
- disease of the lymph nodes
- tropical parasites that invade and block the lymphatics.
Reducing your risk of getting lymphoedema

To reduce your risk of getting lymphoedema, take good care of your skin and follow the points below.

- Keep your skin moisturised.
- Treat cuts, skin infections (including athletes foot), and insect bites quickly, and avoid getting sunburnt.
- Wear gloves when gardening and doing dishes.
- Avoid having blood pressure checks, injects, blood tests, and so on, on limbs that might be at risk.
- Don't use hot water bottles, ice, or heat packs and avoid tight, restrictive clothes.
- Maintain a healthy weight and keep fit.
- Don't wax. If you shave your legs, use an electric shaver rather than razors or hair removal creams, as this is less likely to damage the skin. However, if you do use a razor, keep the blades clean, change them regularly, and use plenty of soap for lubrication.
- Hot spa baths may make the swelling worse, so be careful if using them, and afterwards cool down with cold water.

If you have lymphoedema

Managing your condition

- Wear your compression stockings every day from morning till night.
- Elevate the affected limbs whenever you can, to help the fluid drain out.
- Take good care of your skin and keep it moisturised.
- Avoid insect bites, cuts, scratches, and burns, and if they occur, treat quickly.
- See your doctor immediately if you get any pain, redness, or heat in the affected limb, especially if you also have flu–like symptoms or a fever. If this happens, you may have cellulitis, which is a bacterial infection that needs immediate antibiotic treatment.
- Pay attention to your workplace posture. Check that the way you sit at work, or the type of work you do is not making your lymphoedema worse. For example, heavy lifting or repetitive movements.
Getting treatment

The earlier lymphoedema is diagnosed and treated, the greater the likelihood of success.

- Regular exercise, such as walking, swimming, Pilates, tai chi, and yoga can be very helpful.
- Lymphatic massage helps to move the lymph out of the swollen limb. You can learn to do this yourself from a lymphoedema therapist.
- Compression bandages and stockings squeeze the fluid out of your legs when you are standing up. They need to be fitted by a lymphoedema therapist or other trained person. You must wear them according to the therapist's instructions. When cared for according to the manufacturer's instructions a garment should last around four months.

Lymphoedema specialists are usually nurses, physiotherapists, or massage therapists who are specially trained in lymphoedema management. They provide several types of treatment including bandaging massage, exercise, and taping.

Support

You may also find it a great help to talk to other people with lymphoedema, as they can provide support, advice, and experience. Check with your local Cancer Society for lymphoedema support groups or education sessions in your area.

Other treatment options

Other treatments for lymphoedema include:

- External Pneumatic Compression device. This is a pneumatic boot that inflates and deflates to squeeze fluid out of the leg. It is normally used in the evening to get rid of any fluid that has built up despite using the compression stockings.
- Surgery: Many operations have been tried to cure lymphoedema, but none have been successful. If your leg remains very swollen even after compression therapy, it may be recommended that you have surgery to reduce the size of the lower leg. This is called Homan's reduction.

Note: Diuretics (substances that increase urine) are not useful in managing lymphoedema.