

This information has been produced and verified by accepted experts in their field. It reflects current best practice and evidence-based research where appropriate. It has been designed to assist you in managing your condition and is not intended to replace advice you may receive from your healthcare practitioner. If you or your healthcare practitioner would like to ask any questions, provide us with feedback or require details of the research used to develop this information, please contact the Lymphoedema Support Network on 020 7351 4480.

Why am I reading this leaflet?

You have been diagnosed with lymphoedema, but don't panic or worry – you are not alone! There are specialist healthcare professionals who can help, offer advice and information, as well as support groups (like the LSN) who are here to help you understand and deal with this condition.

What is lymphoedema?

Lymphoedema is a swelling that does not go away, but it can be controlled. It can affect any part of the body, but usually causes swollen arms or legs. Lymphoedema develops when the lymphatic drainage system is unable to work properly, resulting in a build up of lymph (a colourless fluid) in the tissues, which causes swelling beneath the skin. There are two types of lymphoedema:

Primary lymphoedema occurs because the lymph system does not develop properly. Lymphoedema is often present at birth but can also come on later in life. Sometimes primary lymphoedema can be inherited from members of your family in the same way as the colour of your eyes.

Secondary lymphoedema develops when there has been some sort of damage to the lymphatic system and can be caused by some types of surgery, radiotherapy, repeated skin infections, severe injury or burns.

Lymphoedema is **NOT** something you can catch and you cannot pass it on to someone else by contact with them.

What does the lymphatic system do?

The lymphatic system plays an important part in the way that the body functions, for two reasons:

- It helps drain fluid, proteins, cells and waste products from the skin and tissues
- It is part of the body's immune defence against infection

How will lymphoedema affect me?

Lymphoedema is a result of fluid building up under the skin and in the tissues. It can be uncomfortable, especially towards the end of the day when there may be more swelling and joints become stiffer and ache. This may result in you feeling very tired. Lymphoedema may make other parts of the body ache: for example, if you have a swollen leg, the extra weight of your leg may cause your back to ache. Your other leg may also feel the strain, as it has to work a little harder. If you have arm lymphoedema, your shoulders may feel tight and uncomfortable.

Because your lymph system is not working as well as it should, you might develop a skin infection in your swollen limb, known as cellulitis (pronounced: sell-yoo-light-us). Symptoms include inflammation (redness), swelling, pain, fever or vomiting, flu-like symptoms or a general feeling of being unwell. Infection should be treated immediately with antibiotics, so contact your doctor as soon as possible.

When travelling, having a course of antibiotics in your wash bag may prove helpful (important if you have had an infection before), especially if you are on a gap-year or travelling for some length of time. Ensure you keep them in your hand luggage, reducing the risk of them being lost in your suit case. Repeated attacks of cellulitis may require you taking a small dose of antibiotic every day. **For more information on this see the LSN fact sheets 'What is Cellulitis?' and 'Management of Cellulitis in Lymphoedema'.**

Will it ever go away completely?

At the moment there is no cure for lymphoedema. However, with treatment it can be improved and controlled, enabling you to get on with everyday life. There have been exciting research advances which have improved understanding and will lead to more effective treatments.

Once you have been diagnosed with lymphoedema, you will be referred to a specialist – the LSN has a directory of treatment centres that your doctor can refer you to.

What is the treatment for lymphoedema?

There are four main elements to treatment:

Skin care, Compression, Exercise and a specialist form of Massage.

1. Skin care

Because your lymph system is not working as well as it should, it harbours more 'bugs' (bacteria and fungi) and makes you more likely to get an infection (cellulitis). In order to reduce the risk of infection, your skin needs extra attention. This means:

- Checking your skin for signs of redness, scratches, cuts, bites, stings and grazes. Using insect repellent on holiday is also a must!
- Washing skin carefully and paying special attention to drying between the fingers and toes.
- Keeping skin soft and supple. Skin can become dry and cracked easily so it is vital to moisturise your limb every day.
- Fungal infections such as athlete's foot are common and if untreated can lead to more serious infections such as cellulitis. It's important to see your doctor as soon as possible for anti-fungal treatment. Prevention is better than cure – Tea Tree oil is particularly helpful.
- Avoid any trauma or injury to the skin on swollen limbs. If you cut or graze the skin, apply antiseptic cream immediately and report any signs of infection to your doctor as soon as possible in case antibiotics are needed.
- Protecting the swollen limb from injury is recommended where possible – wearing slippers/'Crocs' around the house and flip-flops on the beach if you have foot swelling; gloves to protect hand swelling when gardening.
- Ingrowing toenails may also be a problem for many with toe swelling – pay careful attention to cutting nails and see a chiropodist or podiatrist if problems persist.
- Sun protection is also important – the swollen limb is not often exposed to the sun, so high factor sun creams are recommended (at least SPF 30).

For more information see the LSN fact sheet 'Skin Care for People With Lymphoedema'.

2. Compression

Compression is a vital part of treatment that helps maintain/optimize the size and shape of your swelling. There are different types of compression used in lymphoedema treatment and your lymphoedema practitioner will discuss which is the best for you. So that you have an idea of what to expect, it may include:

- a) An elastic compression garment (sleeve or stocking) to wear on the affected limb. Compression garments come in a variety of styles and degrees of strength

and although you may feel unhappy about wearing them, they really are essential to stop your swelling worsening. You may have seen sports people such as footballers and runners wearing these as they also improve circulation. They should be comfortable and supportive and are absolutely key in treating lymphoedema (without them swelling gets worse and uncomfortable). Usually, these are worn all day and removed at night – however, talk to your lymphoedema practitioner about what is best for you.

For more information see the LSN fact sheet 'The Use of Compression Garments in Lymphoedema Management'.

- b) Compression bandages which are applied in layers and in a method known as Multi-Layer Lymphoedema Bandaging (MLLB). The layers of bandage include a layer of wadding or a thin foam bandage close to the skin (to help improve the shape) followed by firm bandages, which act as a rigid support for muscles to work against. This improves the size and shape of the limb and reduces the tightness and heaviness. Bandages are worn day and night and will be reapplied frequently for 2-3 weeks. Once the bandages have improved the shape and size of the swelling, a compression garment (see above) will be fitted to enhance the results. Bandages make exercise (through the muscle contractions) more effective at improving fluid drainage. Bandages achieve little without movement and exercise so they need to be comfortable and yet still allow you to move.

For more information see the LSN fact sheet 'Multi-Layer Lymphoedema Bandaging (MLLB)'.

3. Exercise

Regular exercise while you are wearing your compression will help you to control your swelling. Any movement means the muscles produce a pumping action on the lymph vessels, sending fluid and waste products back into the body for processing and removal. A gradual and steady increase in regular exercise can make all your body systems work more efficiently. Exercise can also help keep your weight within normal limits which is good for people with lymphoedema.

Avoid sitting or standing for longer than 30 minutes, as this can make swelling worse. Stand up regularly and walk around for a few minutes. Discuss with your lymphoedema practitioner some simple exercises you can do. It can be difficult to arrange time to do this during the day, particularly during lessons, but careful planning with your teachers/tutors can help.

Gentle, regular exercise like swimming, walking and cycling can help reduce swelling. Your lymphoedema practitioner will talk to you about suitable exercise, give you special exercises to do at home and advise you on how to continue with activities and sports you enjoy.

You should always wear your compression garments when exercising and if there is any risk of injury, wear suitable clothes and appropriate protective gear. You will need to be careful if playing contact sports like football or rugby as getting knocked or falling over can increase swelling and risk of infection, but many people with lymphoedema do play sports and you should not let the condition stop you.

Try and leave your stockings on for at least an hour after exercise to maximise the effect, after that you can take them off for showering.

You do not need to wear the garment when swimming as the water supports your limb, but they should be put back on after you are dry. Nevertheless, you may find wearing an old garment when swimming does work better.

Try to find what leisure activities and sports you enjoy and are comfortable with. You may have to adapt to some restrictions, but there is no hard and fast rule.

For more information see the LSN fact sheet 'Recreational Exercise with Lymphoedema'.

If you are travelling for some hours, and especially on long flights, there are ways you can help prevent any further problems with swelling. Wear your compression garments, walk around and exercise your legs and feet when you can. You should also drink plenty of water to prevent becoming dehydrated and avoid alcohol.

For more information see the LSN fact sheet 'Holidays and Travel for People with Lymphoedema'.

4. Massage

Manual Lymphatic Drainage (MLD) massage is very different from other types of massage and is carried out by specially trained therapists. MLD treatment is specialised; the aim being to stimulate lymph drainage by lightly stretching and releasing the skin. This helps to draw fluid into the lymphatics and move fluid away from the swollen, congested areas of the body. You can also do a simplified version of MLD for yourself, called Self Lymphatic Drainage (SLD), which your lymphoedema practitioner can teach you how to do.

For more information see the LSN fact sheet 'Manual Lymphatic Drainage for People with Lymphoedema'.

Will Lymphoedema affect my choice of careers?

People with lymphoedema have diverse and successful careers. Seek as much advice as you can from your careers advisor, people who are already trained and working, and potential future employers and talk to them about your condition so that they can give you advice as to whether particular careers are suitable for you.

How will people react to my lymphoedema?

Most people are nervous when starting a new school, college, university or even meeting new people. However, your friends will still be your friends and while it can be hurtful if some people react in a negative way because you have a swollen limb, many people may not even notice your lymphoedema.

There will be times when you feel down; you may feel it's frustrating and unfair if you can't wear the latest fashions, or you spend hours searching for a pair of shoes that fit.

Choose clothes that show off your good points and that you feel comfortable and confident in. Although expensive, bespoke footwear (see the LSN fact sheet on foot swelling) and clothing can be obtained e.g. Levi's offer a made-to-measure jeans service.

Be as positive as you can, and remember that you are not alone. There are many other young people with the same condition and going through similar experiences and feelings. It can be helpful to meet others who also live with lymphoedema. Your lymphoedema practitioner may have other teenagers who would like to meet up and share notes/ideas/support. There are online forums that you may find interesting such as:

- The LSN's Facebook page called 'Lymphoedema Support Network'
- You can follow the LSN on Twitter @lymphsupport
- The LSN's HealthUnlocked online community forum at <https://healthunlocked.com/lsn>
- Snapchat may also be helpful

Your family and lymphoedema specialists will offer support, treatment advice and guidance, but you must play your part to help manage the swelling. If you are having difficulties with anything, contact your clinic or the LSN for advice, it may be that a simple solution can be found that would make life much easier.

Meeting others with lymphoedema may also prove helpful – LSN works closely with the Children's Lymphoedema Special Interest Group (CLSIG) who facilitate bi-annual events (Lymphaletics) for children and teenagers with lymphoedema (and their families) to meet up, exchange ideas, and have fun through exercise. Contact the LSN for details of the next event.

Alternatively, please contact the LSN if you would like to be put in touch with young people who have lymphoedema or if you could offer someone else support.

Comments from some young people living with lymphoedema

*"I am studying for a sports science degree and my part time job is as a swimming instructor and lifeguard – I cope with lymphoedema and am able to do most things"
"Don't let it rule your life – I'm continuing with college as normal"*

"Being confident and accepting my condition helped me feel happy with what I wore and who I am"

"Wind surfing and sailing are my two major sports. I tend to wear a short wet suit and a compression stocking"

"I have been able to play all types of sport especially football and basketball. I love swimming and lots of other sports too"

"My friends and family have helped me a lot, especially my mum, she has been a star, she's always motivating me to put my stockings on"

"People are as nice and as mean to me as they are to everyone else which is great"

"I spent four months in Majorca working and this was a testing time for me. I feel I coped very well – it has made me a stronger person and I know that I can cope with it on my own"

"Although I love skiing holidays, finding boots to fit my lymphoedema has proved difficult. Snow boarding is an alternative (the boots are much softer!) – and I now love this sport even more – but can still enjoy the family! There is always a way around things. Don't let having lymphoedema put you off doing something you love!"

Five things to remember

- Lymphoedema is a swelling that usually affects arms and legs.
- Lymphoedema is not something you can catch from contact with other people.

- Lymphoedema can be managed through skin care, compression, exercise and massage.
- If you notice signs of infection, including cellulitis, seek help straight away.
- Most importantly: stay positive, follow the advice of your lymphoedema practitioner and play your part in managing your lymphoedema.

Contributors

Denise Hardy, Clinical Nurse Specialist – Lymphoedema, Kendal Lymphology Centre, Cumbria.

LSN Nurse Advisor. 1, 2

Dr Jacquelyne E. Todd, Physiotherapist Consultant in Lymphoedema, Leeds Lymphoedema Service. 1

Helen Young, Nurse Consultant in Lymphoedema at St. Giles Lymphoedema Clinic, Lichfield. 1

Gail Close, Senior Nurse Practitioner. 1

Karen Crowley-Jenns, MSc RGN, Clinical Nurse Specialist. 1

Glen Brice RGN BSc (Hons) Clinical Genetics, St George's University of London. 1

Marie Todd, Clinical Nurse Specialist in Lymphoedema, Glasgow. 1

George Cole – lymphoedema patient. 2

Professor Peter S. Mortimer, Consultant Dermatologist at the Royal Marsden and St. George's Hospitals, London. 1, 2

LSN Trustees. 1, 2

LSN members. 1

1. Previous contributor

2. Member of 06/2018 contributors' review panel

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

Telephone: 020 7351 4480 (Information and Support)

020 7351 0990 (Administration)

Facsimile: 020 7349 9809

e-mail: admin@lsn.org.uk

Website: www.lymphoedema.org

Registered Charity No. 1018749

Patron: Zoë Wanamaker CBE

Honorary Patron: Dame Judi Dench, CH, DBE



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