

Lymphoedema

your questions answered



This booklet is to inform patients about lymphoedema and its treatment.

Lymphoedema is a swelling, which occurs due to a failure of the lymphatic system. Swelling occurs most commonly in the limbs, but can occur in other parts of the body and can affect people of all ages.

It is a chronic condition, which tends to progress if left untreated. It is important to remember that lymphoedema can be treated successfully in order to prevent this progression and improve quality of life.

For the majority of patients, this can be achieved by specialist treatment, known as Complex Decongestive Therapy (CDT). The goal of this therapy is to reduce the swelling and maintain freedom from symptoms. CDT is virtually free from side-effects and is the treatment of first choice for lymphoedema. It is important that patients have an understanding of lymphoedema and its treatment. This will help them to maintain the benefits of therapy and manage their condition.

People who may be at risk of developing lymphoedema, e.g. those with a family history of lymphoedema, or those who undergo surgery/radiotherapy treatment for cancer, should be aware of preventative measures to take to help avoid lymphoedema developing. It is also very important that they are aware of the signs and symptoms of lymphoedema and that early detection and prompt treatment is always recommended.

“... I now after a long time can see a light at the end of the tunnel. I have found this treatment nothing short of miraculous. Please, please make it part of our road to recovery and a normal life.”

Lymphoedema patient in Northern Ireland

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1. WHAT IS THE LYMPHATIC SYSTEM?

Most people will be aware that there are systems of veins and arteries in the body to carry blood to and from the heart. There is also another system which acts as a transport and drainage system. This is known as the lymphatic system. (Fig. 1)

This system has several major functions including playing a vital role in the body's defence against infection.

Lymph is a colourless fluid, which forms in the tissues of the body. It consists of proteins, water, fat, various cells, waste products and other foreign substances. It normally drains back into the bloodstream through a network of lymph vessels and lymph nodes/glands. As lymph travels through this network of vessels and nodes, dead or abnormal cells and other waste products are removed, and then it is returned to the bloodstream.



Fig. 1

The lymphatic system (shown in green) works in harmony with the blood circulation system with its veins (blue) and arteries (red).

2. WHAT IS LYMPHOEDEMA?

Lymphoedema is a build-up of lymph fluid in the tissues which causes swelling in the affected area. It is due to a failure of the lymphatic system and most commonly occurs in the arm(s) or leg(s), but can also be found in the head, neck, genital area, chest and abdomen. (Fig. 2) It can affect people of all ages, including infants and children. (Fig. 3)

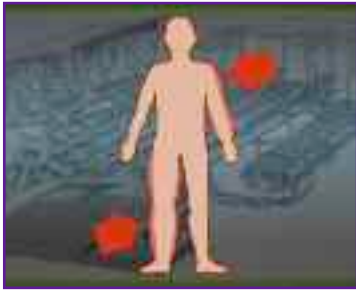


Fig. 2



Fig. 3

Lymphoedema is a swelling which can be distressing and painful. It can significantly affect your quality of life. You may experience difficulty in carrying out simple everyday tasks and in finding clothes or shoes to fit. Despite this, it is important to remember that lymphoedema is a **treatable** condition.

It is much more common than most people realise, and is currently estimated to affect 2,500 to 3,000 people in Northern Ireland, although this figure is likely to be an underestimate.

3. WHEN DOES LYMPHOEDEMA OCCUR?

If the lymphatic system fails to work normally, a build-up of fluid (lymph) develops in the affected area, which can eventually become swollen. This swelling is known as lymphoedema.

There are **two types** of lymphoedema:
Primary and **Secondary**.

Primary lymphoedema is due to an abnormality of the lymphatic system, which is present from birth. It often runs in families and can be due to an underdeveloped or abnormally functioning lymphatic system. When the lymphatic system can no longer cope, swelling develops. This can occur in infants, children and adults.

Secondary lymphoedema can occur following damage to a normal lymphatic system. This can be as a result of surgery (e.g. the removal of lymph nodes during surgery for cancer), or as a side effect of radiation treatment for cancer. It can also occur as a result of Chronic Venous Insufficiency, or after injury, scarring, or infection of the lymphatic system.

Both types of lymphoedema progress through the same stages:

Stage 0 (Latent stage)

In this early stage, there is no obvious swelling. The lymphatic system has however been disturbed e.g. by surgery, trauma, infection, etc. or by abnormalities present from birth and there is a risk of lymphoedema developing at any time. It is therefore important that you are given advice about avoiding further damage to the lymphatic system so that the risk of lymphoedema developing can be reduced.

Stage I (Reversible stage)

During this stage the lymphatic system has been overloaded causing swelling to develop in the affected area. This swelling can be indented by applying pressure. When the affected arm or leg is raised, the swelling will gradually reduce.

Stage II (Spontaneously irreversible stage)

In this stage the swelling cannot be indented by applying pressure and raising the affected area no longer reduces the swelling. The texture of the swelling changes due to a gradual hardening of the tissues, which is known as **fibrosis**.

Stage III

In this, the most advanced stage, the swelling is severe, the skin becomes harder and large bulges may develop. There is also a much greater risk of infection and development of wounds in the affected area.

4. CAN LYMPHOEDEMA BE TREATED?

In most cases the answer is YES.

With the correct treatment - Complex Decongestive Therapy (CDT) - the swelling and condition of the skin can almost always be improved. However, if you suffer from certain medical conditions, this can sometimes mean that treatment will not be possible, or may have to be adapted to suit your needs.

Early detection and diagnosis of lymphoedema by your doctor is essential.

Prompt treatment is always recommended when the swelling is soft and more easily managed.

Lymphoedema should be treated as **early** as possible in order to prevent complications, such as infections, fibrosis and increased swelling. It is important however to remember that treatment is still effective at later stages, although a longer period of treatment may be required to reduce swelling and break down fibrosis.



Before and after
Complex Decongestive Therapy (CDT) Treatment



5. WHAT CAN BE DONE TO HELP?

If your doctor has diagnosed that you have lymphoedema, you should be referred to a fully trained and certified lymphoedema therapist.

The treatment you will receive is known as Complex Decongestive Therapy (CDT). CDT is regarded as the treatment of first choice in the management of lymphoedema and consists of **two phases**, symbolised here by the two circles.



Phase 1 - **Intensive Phase** (blue)

Phase 2 - **Maintenance Phase** (green)

Phase 1 - The Intensive Phase aims to reduce the swelling as much as possible and to start to break down any fibrosis which may have developed. You will also be taught skills to help you to manage your condition.

Phase 2 - The Maintenance Phase aims to maintain and further improve the treatment outcome of Phase 1.

Phase 1 - The Intensive Phase of treatment must include the following four components:

(i) Manual Lymphatic Drainage (MLD)

MLD is a gentle manual treatment that improves the function of the body's lymphatic system. MLD gently mobilises fluid out of a swollen area into healthy lymph vessels that drain into the blood stream.



(ii) Multi-layer compression bandaging

The use of multi-layered bandages increases the tissue pressure and helps to prevent the re-accumulation of swelling between treatments. Bandaging can also help to break down areas of fibrosis and reshape the limb until it is ready to be fitted with a medical compression garment.



(iii) Skin and nail care

A common complication of lymphoedema is that there is an increased risk of infection such as cellulitis. Careful skin, nail care and hygiene are essential to minimise the occurrence of such infections.



(iv) Exercises

The bandaged limb should be exercised regularly. This activates the muscle and joint pumps of the affected limb, which over time can further help to reduce any swelling.



It is necessary that **all four** components are carried out during your treatment, regardless of the severity of your swelling. With patients' full cooperation expertly performed CDT should result in the swelling being reduced or almost eliminated.

HOW LONG WILL THE TREATMENT LAST?

The treatment takes approximately one-and-a-half hours per day for a minimum of two weeks in the early stages of lymphoedema. Treatment may last up to six weeks if your lymphoedema has become more advanced. This is because a greater amount of time is required to help improve the skin condition and to help break down and soften any fibrosis.

When your limb is as free as possible from swelling, you will be measured for a medical compression garment. To ensure an exact fit and correct compression - essential for effectiveness and comfort - it is recommended that you should be accurately measured for custom-made garments by your therapist or by specially trained personnel. (Fig. 4)



Fig. 4

Two garments should always be supplied to allow for washing and to enable you to wear your garment at all times during the day. Your compression garments should be replaced by your therapist every 6 months to ensure they remain effective.

Phase 2 - The Maintenance Phase of treatment is 'life-long' and ideally should include six monthly checkups and further periods of intensive treatment (CDT) as required.

It consists of:

- Wearing compression garments daily
- Regular MLD as indicated by your therapist
- Exercises to do at home
- Skin and Nail care
- Self-treatment as indicated by your therapist



Fig. 5

When patients cooperate fully with Phase 2 of CDT and especially wear their compression garments at all times during the day, they can keep swelling to a minimum. (Fig. 5)

6. WHAT PRECAUTIONS OR PREVENTATIVE MEASURES SHOULD I TAKE?

If you are at risk of, or have already developed lymphoedema, it is very important that you are aware of the following precautions:

SKIN CARE

It is vital that the affected area is cleansed and moisturised daily with non-scented cream to reduce the risk of infections, such as cellulitis, developing. (Fig. 6)

Any injury to the affected limb or area will increase your risk of infection and further swelling. If you feel generally unwell or have any signs of infection such as increased temperature or hot red tender swelling you must contact your doctor immediately, so that suitable antibiotics can **URGENTLY** be prescribed for you.



Fig. 6

Patient with cellulitis in left leg

BY TAKING THE FOLLOWING PRECAUTIONS YOU CAN HELP TO REDUCE YOUR RISK OF INFECTION:

AVOID	USE
cuts	washing-up gloves / thimble / emery boards
scratches	gardening gloves / wear long trousers when gardening
burns	oven gloves
razors	electric razors
insect bites	insect repellents
fungal infections	hygiene / meticulous skin care
sunburn	high sun protection factors



TRAUMA

To reduce the risk of infection you should also avoid:



- Injections in the affected limb/area



- Acupuncture in the affected limb/area



- Blood samples being taken from the affected limb/area



- Blood Pressure readings in the affected limb



- Extremes of hot or cold e.g. very hot baths, saunas or over-exposure to the sun



- Tight, restrictive clothing eg tight bra straps, waistbands, watches etc.

7. GENERAL RECOMMENDATIONS

- Try to use the swollen arm or leg normally because using the muscles will help to improve lymphatic circulation.
- Avoid over-exertion as this may increase swelling.
- If your arm is at risk or swollen avoid lifting or carrying heavy objects.
- If your leg is at risk or swollen do not go barefoot and avoid standing or sitting for long periods.
- It is very important to keep your weight within normal limits.
- Keep the affected limb clean and well moisturised. This will help to reduce episodes of infection.
- If possible, try to keep the affected limb raised for short periods throughout the day.
- Seek professional advice from your therapist before flying because this may cause increased swelling.

**Do not delay in getting medical attention.
The earlier the condition is treated, the better.**

8. AIMS AND OBJECTIVES OF THE NORTHERN IRELAND LYMPHOEDEMA SUPPORT GROUP (NILSG)

NILSG was established in 2002 by a small group of people with lymphoedema together with their physiotherapist.

It aims to:

1. Provide support for people with lymphoedema
2. Provide information about lymphoedema and its treatment
3. Work towards the availability of better resources for lymphoedema treatment
4. Work in partnership with local healthcare professionals and others involved in the statutory and voluntary sectors

9. WHAT NILSG OFFERS

1. Telephone helpline **028 9066 7570**
2. Current information about lymphoedema and its treatment in Northern Ireland and overseas
3. Support Group meetings twice a year
(for details see NILSG website: www.nilsg.co.uk)

We would like to encourage everyone affected by lymphoedema, to join our support group where they will be made most welcome.

10. ACKNOWLEDGEMENTS

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A large print version of this booklet is available in PDF format via our website: www.nilsg.co.uk.

Useful local contacts:

The Lymphoedema Network Northern Ireland (LNNI)
www.lnni.org

The Northern Ireland Cancer Network (NICaN)
www.cancerni.net

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Northern Ireland Lymphoedema Support Group (NILSG)

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Northern Ireland



Lymphoedema

SUPPORT GROUP