



National  
Lymphoedema  
Services

# Information Booklet

## For Upper Body Lymphoedema

### Patient Booklet





## Introduction

This information booklet tells you more about Lymphoedema and how best to manage it.

Lymphoedema is a build-up of lymph fluid that causes swelling. It can affect any part of the body, but it most commonly affects the arms or legs. It develops when your lymphatic system does not work properly.

As lymphoedema is a long-term condition, self-care is really important. You may have to change your lifestyle in certain ways to cope with it. But once you make those changes, you will be able to live an almost normal life without too many restrictions.

## What is the lymphatic system?

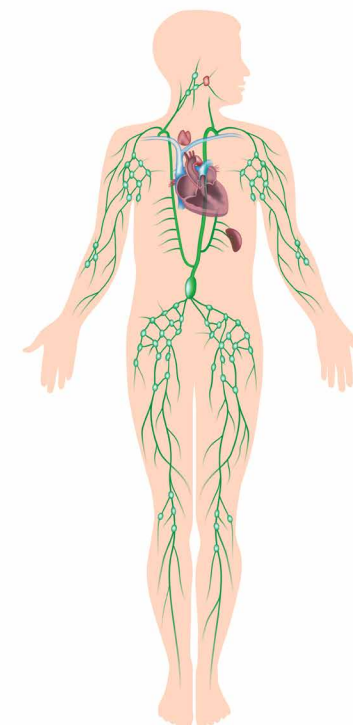
**Our bodies have a network of lymph nodes and vessels that collect and carry lymph fluid from all parts of the body, much like veins collect and carry blood.**

**Lymph fluid** is made up of proteins, salts, water and white blood cells. Lymph fluid carries waste products from our cells and internal organs, and the white blood cells fight infections.

**Lymph vessels** carry lymph fluid round the body. They have valves to stop the fluid going the wrong way. Muscle activity keeps the fluid moving.

**Lymph nodes** are glands that filter harmful substances out of the lymph fluid. White blood cells collect in the lymph nodes to fight infection from viruses or bacteria. Clusters of lymph nodes are found in the neck, armpits and groin.

## Lymphatic system



The lymphatic system has **three** main roles

- It forms part of your immune system, as it makes white blood cells that fight infection.
- It cleans your tissues by removing waste products.
- It helps to maintain a balance of fluid in your body by draining away the excess.

## What is lymphoedema?

Lymphoedema is a condition that causes swelling. It occurs when the lymphatic system does not work properly. It mainly affects the arms and legs but can also occur in the trunk, breast, head and neck, groin and genital areas.

There are two types of lymphoedema:

**Primary lymphoedema** is a genetic condition where the lymph system does not develop properly. It may be present from birth or triggered later in life.

### Secondary lymphoedema

Secondary or acquired lymphoedema results from damage to the lymphatic vessels or lymph nodes. The damage may be caused by:

- Cancer treatment
- Infection such as cellulitis
- Trauma such as a fracture, wound or other injury
- Obesity
- Mobility problems, for example arising from spina bifida
- Other forms of oedema (swelling), such as oedema caused by deep vein thrombosis, varicose veins or other problems with blood circulation

Lymphoedema that is a result of cancer treatment can develop at different rates. It can develop several months or several years after treatment.

## Can my body compensate for damage to the lymphatic system?

Lymph nodes cannot regenerate, but in some cases the body finds ways of compensating for the damage to a certain extent. For example, the body can stimulate existing lymph vessels to become more efficient or create connecting branches to other lymph vessels or veins.

The development of secondary lymphoedema depends on how well your lymphatic system compensates and how much stress it is under.



**Stage 0** - The lymphatic system is still coping through various forms of compensation. No oedema (swelling) is present.

**Stage 1** - The lymphatic system is overburdened and a soft pitting swelling develops. (Pitting means you can make a dent in your skin by finger pressure.) The swelling goes down when you keep the limb raised.

**Stage 2** - Fibrosis sets in when swollen body tissue becomes inflamed and produces collagen fibres. The skin feels hard and does not pit so easily. Raising the limb no longer reduces the swelling.

**Stage 3** - The swelling is extreme and does not pit. The skin is hardened and shows wart-like growths. The risk of inflammation is high and wounds do not heal well.

## How do I manage my lymphoedema?

Lymphoedema is progressive and will become steadily worse unless it is managed. The sooner you begin a suitable programme of therapy, the better are your prospects of preventing its progression and of improving your condition.

Managing lymphoedema involves four main approaches:

- **Compression garment**
- **Skin care**
- **Exercises and activity**
- **Self-lymphatic drainage (SLD)**



Your lymphoedema specialist will provide you with a compression garment such as a special stocking, advise you on skin care and exercise, and show you how to do self lymphatic drainage (SLD). SLD is a type of self-massage that helps to move excess fluid out of a swollen area.

If necessary, your lymphoedema specialist may also recommend a course of intensive treatment called **complex decongestive therapy**. This lasts one to three weeks. It includes:

- **Manual lymphatic drainage (MLD)**
- **Multi-layer bandaging/compression**
- **Exercise**

MLD is a specialised form of massage. It is used only until the swelling has gone, and only as part of a complex decongestive therapy plan.

For more information on complex decongestive therapy, see page 20 below.

## Introduction

Careful daily skin care is essential in managing lymphoedema. Healthy intact skin is the body's primary line of defence against invading bacteria. Bacteria can cause infections such as cellulitis, which can worsen the swelling. By looking after and protecting your skin, you reduce your risk of infection.

## Recognising cellulitis

Any break in your skin can allow bacteria to enter, which can lead to cellulitis. Breaks in the skin can include wounds, scratches, insect bites or inflammation caused by conditions such as athlete's foot, eczema or dermatitis. However, it's not always possible to identify the cause, and cellulitis can occur without warning.

The infected area can develop a rash or become red, hot and tender to the touch. The redness can develop over a few hours and start spreading. You might feel unwell at first, as if you are coming down with flu (but not always). Symptoms can include fever, shivers, muscular aches and pains, headache, nausea and vomiting.

If you experience any of these signs, **contact your GP immediately** as you may need antibiotics.

Treating cellulitis as soon as possible reduces stress on the lymphatic system and can prevent lymphoedema from getting worse.

**For more information on cellulitis, see:**  
<https://www.hse.ie/eng/services/list/2/primarycare/lymphoedema/celluitis-and-lymphodema.pdf>

## General Skin Care advice:

1. Keep your skin clean and dry. Natural gentle cleansing products with a low pH (slightly acidic) are recommended. Dry your skin gently but thoroughly. Pay special attention to creases in the skin and to the skin between the fingers.
2. Use a non-perfumed, low-pH moisturiser for your skin. Use moisturiser from a pump or tube rather than a tub, which is not hygienic. Apply it before you go to bed at night.

3. If you shave under your arms, use a well-maintained electric razor. Try not use a regular razor as there is a danger of cuts. However, if you do use one, wash the blades in hot soapy water after use and change them often. Treat any cuts with an antiseptic cream.
4. If possible, avoid having needles put into your swollen hand or arm when you have blood tests, injections, a drip (infusion) or acupuncture. An unaffected limb should be used instead – such as a leg if necessary. Ask to have your blood pressure taken on the opposite arm to the one with lymphoedema.
5. Make sure all fabrics that come in contact with your skin are washed regularly. This includes compression bandages and garments.
6. Do not wear tight jewellery or clothing that causes marks or dents on your skin on the swollen side. Ensure your bra fits well.
7. Avoid excessive heat as this can increase swelling. For example, take care with hot baths or showers, saunas, steam rooms and Jacuzzis. Do not sit too close to a fire, stove or other heater.
8. Protect your skin from the sun by covering up with clothes or wearing sun cream with a high sun protection factor (SPF 50). Never use a sunbed.
9. Use clippers to cut your fingernails. If you are getting your nails done in a salon, ask the nail technician not to cut your cuticles.
10. Try to avoid all types of skin damage. Cuts, scrapes, bruises, burns, sports injuries, insect bites, pet bites and scratches can become infected. Be sensible and protect yourself whenever possible. For example:

- **Use oven mitts and long sleeves when cooking or baking.**
- **Wear insect repellent or long sleeves.**
- **Wear rubber gloves when washing dishes or floors.**
- **Wear gloves when gardening.**
- **Be cautious when playing with your pets.**
- **Avoid contact with harsh chemicals or cleaners.**

11. Don't carry anything heavy (bags, shopping etc.) with the affected arm, as muscle strain can make the swelling worse.
12. Check your skin daily for cuts, scratches, burns, bites, hangnails and cracked or torn cuticles. Prevent infection by treating any damage immediately. Wash the area thoroughly, apply antiseptic cream and cover if necessary.



**Top tips on exercising**

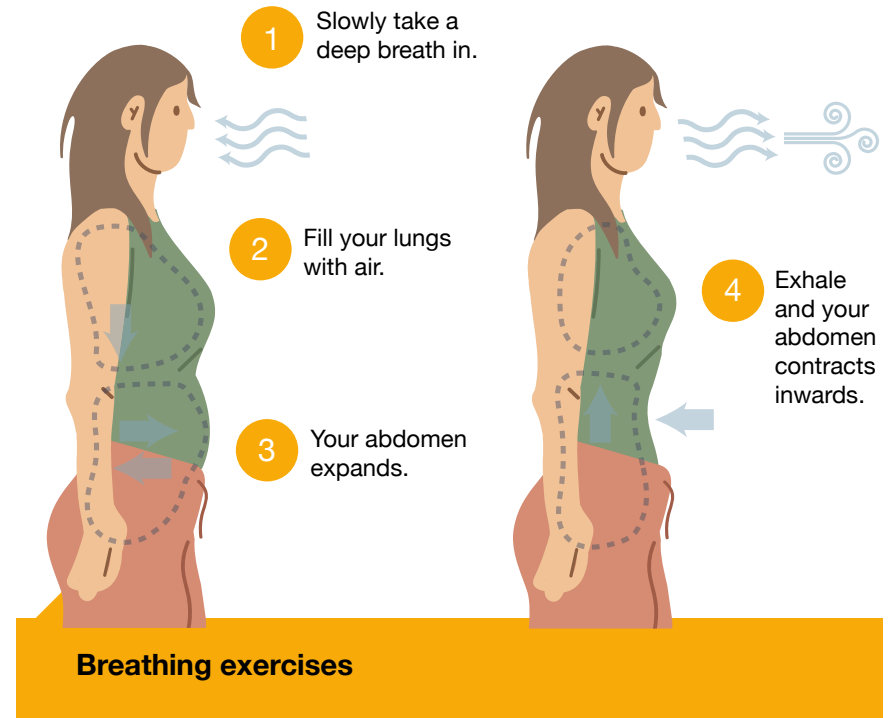
- Always wear your compression bandages/garment(s).
- If your swollen limb(s) feel tired or uncomfortable, ease off or stop completely, and contact your therapist.
- Begin any new exercise slowly and gradually build up the time/distance/ repetitions, depending on the exercise.
- Check with your lymphoedema specialist before starting to exercise with weights or resistance.
- Begin and end every exercise session with breathing exercises (see exercise 1).
- If you are right-handed and your right arm is affected, try to use your left arm for everyday tasks (or the other way round if you're left-handed). Or change hands frequently.
- Exercise in water can be very beneficial. The buoyancy takes the weight off your heavy limb, and the pressure of the water helps with lymphatic drainage.
- Yoga and Pilates are also beneficial. They are gentle forms of exercise that encourage movement, stretching and deep breathing.
- Exercise can take many different forms, including housework, walking the dog or swimming.
- Join a class or group – it will help you feel motivated and make exercise seem less of a chore!
- Create your own support network – you can begin simply by asking a friend or neighbour to go for a walk with you.
- There are often local exercise groups you can join. For example, breast cancer patients may have a local Dragon Boat club. Talk to your healthcare team about what's available.



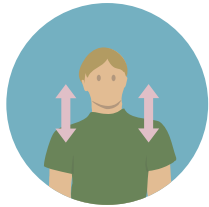
Gentle rhythmical exercises that encourage movement and stretching can improve lymph drainage, joint movement and posture. Try to make them part of your daily routine.

**Exercise 1: Breathing exercise**

- Sit or lie with shoulders relaxed and hands resting below ribs.
- Breathe in through your nose and feel your abdomen rising then slowly sigh out through your mouth.
- Repeat 5 times.



These exercises will help pump fluid through your arm, they should be done in rhythmically at least 3 times a day.



### Exercise 2: Shoulder shrugs

- Shrug your shoulders up and down.
- Repeat 5 times.



### Exercise 3: Shoulder circles

- Circle your shoulders forwards and backwards.
- Repeat each way 5 times.



### Exercise 4: Shoulder abduction

- Lift your swollen arm up to the side as far as it will go.
- Repeat 5 times



### Exercise 5: Shoulder flexion

- Clasp your hands together and lift your arms straight up in front of you, as far as is comfortable.
- Repeat 5 times.



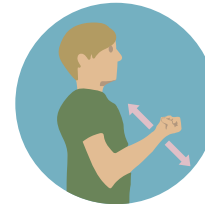
### Exercise 6: Breaststroke

- Place your hands in the prayer position, palms together.
- Push the hands forward extending the arms.
- Separate the hands, drawing the elbows back.
- Return the hands to the prayer position.
- Repeat 5 times.



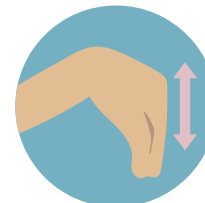
### Exercise 7: Boxing

- Lift your arms up in front of your chest.
- Slowly punch your arms out in front of you, one arm at a time.
- Repeat 5 times.



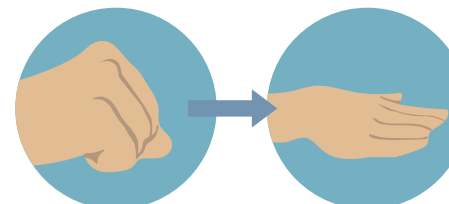
### Exercise 8: Elbow bends

- Bend your elbow and then straighten it again.
- Repeat 5 times.



### Exercise 9: Wrist bends/circles

- Bend the wrist up and down. Repeat 5 times.
- Rotate the wrist clockwise and anti-clockwise. Repeat 5 times in each direction.



### Exercise 10: Making a fist

- Make a fist with your affected hand.
- Straighten your fingers.
- Repeat 5 times.

### What is self lymphatic drainage?

Self lymphatic drainage (SLD) is a simplified version of manual lymphatic drainage. You can do SLD at home. It is a gentle form of massage that helps move fluid away from a swollen area towards healthy lymph nodes where it can be drained more effectively.

SLD starts with massaging areas where the lymph nodes are already working well. This is an essential first stage as it prepares the healthy lymph nodes to deal with extra fluid from the swollen areas.

Your lymphoedema specialist will walk you through this sequence and there are also videos in the list of websites at the back of this booklet.

### Preparation

- Choose a good time and place for the massage. You need a quiet, comfortable place where you won't be interrupted or distracted.
- Allow 15-20 minutes every day to complete the SLD.
- You must do SLD on bare skin. Do not use moisturising cream or oils. You may use talcum powder.
- If you have a compression sleeve, wear this while doing the preliminary massage. Remove it when massaging the swollen arm.
- Do not do SLD if you feel unwell or have an infection.

### Technique

- The massage must be very gentle and not cause skin redness, discomfort or pain.
- Spread your hand to make as much contact with the skin as possible. The more skin you move, the more fluid you move.
- Stretch the skin in the direction shown in the diagrams below. Then release the stretch so the skin moves back.
- A partner or friend can also learn SLD and help you treat areas you cannot reach.



#### Step 1: Breathing

- Sit or lie with shoulders relaxed and hands resting below ribs.
- Breathe in through your nose and feel your abdomen rising then slowly sigh out through your mouth.
- Repeat 5 times.



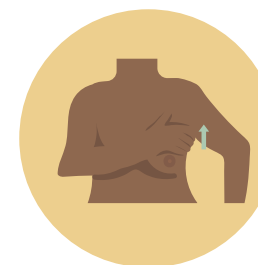
#### Step 2: Neck

- Place your hands on either side of your neck just below your ears.
- Gently stretch the skin down towards your shoulders and release.
- Remember to use the flat part of your fingers and not your fingertips.
- Repeat 5 times.
- Move your hands lower down and repeat so that you have covered the whole neck area.



#### Step 3: Shoulders

- Place the pads of your fingers in the hollow area just above your collarbones.
- Gently stretch the skin inwards towards your neck making a C shape and release.
- Repeat 5 times.



#### Step 4: Armpit

- Place your hand in the armpit on the **non-swollen side**.
- Massage up and into your armpit and release the stretch after each movement. Remember to use the flat part of your fingers and not your fingertips.
- Repeat 5 times.





### Step 5: Chest

- Think of your chest as having three sections: left side, middle and right side. **Starting at the non-swollen side**, massage each section in turn.
- Place your hand flat on the chest and stretch the skin across to the armpit you have just massaged (in step 4 above).
- At positions 1 and 3: repeat 5 times.
- At position 2: repeat 10 times.
- If you have chest wall or breast swelling, you can spend more time working on this area



### Step 6: Back (Leave this step if you do not have help)

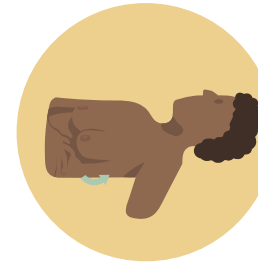
- Think of your back as having three sections. **Start at the non-swollen side.**
- Place relaxed hands on the back and stretch the skin across towards the **non-swollen armpit**.
- At position 1 and 3: repeat 5 times.
- At position 2 repeat: 10 times.

If you have swelling on the chest wall or breast continue with steps 7 and 8. If not, skip to step 9.



### Step 7: Groin

- Place the pads of your fingers in the groin crease on the front of your **hip on the swollen side**.
- Gently stretch the skin up and inwards making a C shape, then release.
- Repeat 5 times.
- Move your hand along the groin and repeat in two further positions to cover the whole groin area on that side.



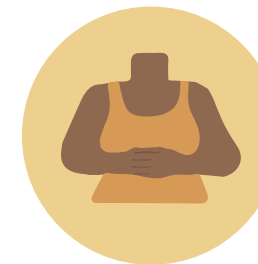
### Step 8: Abdomen

- Think of each side of your trunk area as having three sections: chest and stomach section: position 1, waist section: position 2 and belly section: position 3.
- Start with the belly area just above the hip and stretch the skin down toward the groin.
- At positions 1 and 3: repeat 5 times.
- At position 2: repeat 10 times.

### Step 9: The swollen arm

- Now that the healthy lymph nodes are prepared to absorb more fluid, you can begin to guide the fluid towards them.
- Slowly stroke the skin, up and away from the armpit, towards the neck and across the chest wall.
- Start with 5 strokes at the **top** of the arm, then do 5 strokes from the elbow up and then 5 strokes from the wrist up along the whole length of the arm.
- Always direct your strokes up towards the neck, along the outside of the arm.

### Step 10 Repeat step 1 – breathing.



## Compression garments

Compression garments such as special sleeves or stockings play an important role in managing lymphoedema. They work by:

- **Compressing the swollen tissues and stopping fluid from building up there**
- **Helping to move fluid to an area that's draining well**
- **Supporting your muscles so they can pump fluid away more effectively**

Wearing your garment may feel strange or uncomfortable at first. It should begin to feel more comfortable and supportive within a few days. Discomfort can be eased by slow gentle exercise.

Wearing the garment is **very important** in controlling your lymphoedema.

### Tips for putting on and taking off your sleeve

- Put your sleeve on first thing in the morning when your swelling is at its lowest. But don't try to do this immediately after a shower or bath as it's difficult when your skin is damp.
- The top part of your sleeve should end two finger widths below your armpit.
- Ensure the sleeve stretches evenly over your arm. Rubber gloves can help you grip the material if you need to move it.
- Do not pull the sleeve on or off from the top band as this can overstretch it.
- Moisturise your skin at night after you've taken off your garment, rather than in the morning. This is because moisturising lotion can make the sleeve difficult to put on.



### Tips on wearing your compression garment

- It is important to wear your compression garment all day, but you can take it off at night when you're lying down and resting.
- A new garment may rub and irritate the skin at joint creases. Ask your pharmacist for a barrier cream to help ease discomfort. If it doesn't help, ask your lymphoedema specialist for advice.
- Always exercise with your garment on. Muscle movement against the garment will encourage lymph drainage.
- You will need two garments: one to wash and one to wear. Alternate them evenly so that they last longer and remain elastic. Wash and dry your garments according to the manufacturer's instructions.
- If you're travelling a long distance, especially by air, you should wear your garment for the full length of the journey and for some hours afterwards.

### DO NOT

- Have creases or wrinkles in the garment.
- Fold over the ends of the garment, as this will restrict the blood flow and cause more swelling.
- Cut or alter the garment.

### Remove your garment and tell your lymphoedema specialist if:

- Your fingers start to turn blue or purple.
- You have lasting numbness or new tingling sensations.
- You start to feel short of breath.
- Your garment doesn't fit well or makes your swelling worse.
- Your garment is causing pain or skin irritation.
- You have cellulitis in your limb.

If necessary, your lymphoedema specialist may suggest a course of complex decongestive therapy (CDT) to help manage your symptoms. CDT combines:

- **Manual lymphatic drainage (MLD)**
- **Multi-layer lymphatic bandaging (MLLB)**
- **Exercise**

CDT is also known as decongestive lymphatic therapy or DLT.

### What is manual lymphatic drainage (MLD)?

MLD is a very gentle form of massage and is a key part of CDT. It aims to move fluid away from swollen areas by increasing normal lymphatic activity and bypassing lymph vessels that don't work well.

### Important things to know about MLD

- Only a qualified lymphoedema specialist should perform MLD.
- It is a very light massage and should not cause any discomfort or skin irritation.
- The massage is best done on bare skin, so you will be asked to remove some clothing. If you feel uncomfortable with this, please discuss it with the lymphoedema specialist.
- Your lymphoedema specialist may ask you to lie flat on your back and then on your front during the massage to get the most effective drainage. If you find these positions uncomfortable, please tell the lymphoedema specialist so they can place you in alternative positions.
- You must tell your lymphoedema specialist if any new medical issues arise while you are attending a course of MLD.
- Each session may last up to one hour. You may feel tired, so you should rest and relax in the hours after MLD.
- Make sure you drink plenty of water afterwards.
- It may take a few sessions before you notice an improvement in your swelling.

### What is multi-layer lymphatic bandaging (MLLB)?

MLLB is a system of compression bandaging which is an important part of managing your lymphoedema. It can help prevent the return of the swelling and keep up the improvement you have achieved so far during CDT. Bandaging can help soften any areas of fibrosis (hardened tissue) and reshape the limb. It also helps your muscles and joints to act as more effective pumps for your lymphatic system.

### Important things to know about MLLB

- Several layers of bandages are needed to get the right degree of compression. So it is important to wear loose clothing when you attend for MLLB.
- You may need a friend or family member to help you get home from the clinic after the limb has been bandaged.
- It is important to exercise when wearing your bandages.
- The bandages will feel bulky and restrictive but should **never** cause pain, pins and needles, numbness or discolouration of the fingers. If you get any of these symptoms, remove the bandaging immediately and contact your lymphoedema specialist. Do not try to put the bandages back on yourself.



### What happens after a course of CDT?

After a successful course of CDT, your lymphoedema specialist will guide you on how to manage your symptoms. This will involve a maintenance programme covering four important areas:

- **Skin care**
- **Exercise**
- **Self lymphatic drainage**
- **Compression garment**

Remember lymphoedema is a chronic condition. It is important to keep up a maintenance programme to manage your symptoms. Your lymphoedema specialist will monitor your condition through regular check-ups and should re-measure you every six months for a new compression garment.

## Diet

There is no special diet that will control lymphoedema. However, you should eat a well-balanced diet that includes vegetables and fruit. You should lower your intake of salt, as salt can increase your swelling by making your body retain fluid.

## Maintain normal weight

Try to keep your weight within the normal range for your height by following a healthy balanced diet. If you are overweight, your swelling will be far more difficult to treat. You will find that, if you gain weight, your swollen limb will become worse.

## Keep hydrated

It is important to drink plenty of water, to help your body remove impurities. Cutting back on fluids does not reduce your swelling. If you drink less fluid, the swelling will increase because lymph fluid that is rich in protein will attract more fluid from other parts of the body. You should reduce caffeine and alcohol as they lower fluid levels in your body by making the kidneys produce more urine.



Date	Type of garment	Pressure range	Size	Colour/additions

## Lymphoedema Clinician Contact Details:

Therapist:

Phone:

Email:

## Useful Organisations and Websites

### **HSE Lymphoedema Information**

[www.hse.ie/lymphoedema](http://www.hse.ie/lymphoedema)

### **Europa Donna**

[www.europadonnaireland.ie](http://www.europadonnaireland.ie)

### **Lymphoedema Ireland**

[www.lymphireland.com](http://www.lymphireland.com)

### **Lymphoedema Network Northern Ireland (LNNI)**

[www.lnni.org](http://www.lnni.org)

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

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

### **The British Lymphology Society**

<http://www.thebls.com/pages/everybodycan>

### **Videos about lymphoedema**

<https://pocketmedic.uk/wellbeing/lymph/>