



National
Lymphoedema
Services

Information Booklet

For Head and Neck
Lymphoedema

Patient Booklet




Lymphoedema
IRELAND

Lymphoedema Specialist Contact Details

Therapist:

Phone:

Email:

Appointment Schedule

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Introduction

You may have Lymphoedema as a result of having had surgery and/or radiotherapy to your head/neck. This leaflet provides specific information and advice about managing your Lymphoedema.

It is common to experience swelling immediately after surgery due to the trauma as well as the removal of the lymph nodes. Your body will usually adapt to this change; however, if the swelling remains for longer than 3 months, this is called Lymphoedema.

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.

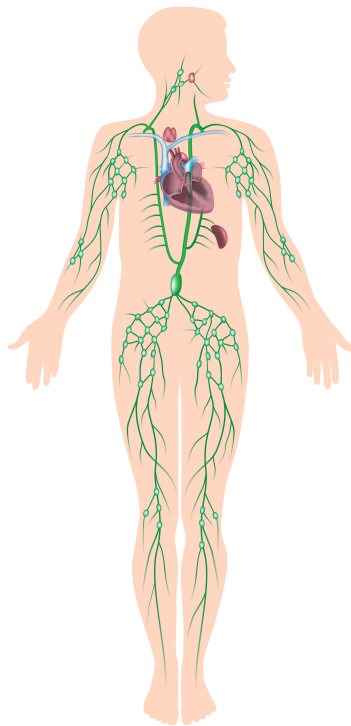
Lymph fluid is made up of proteins, salts, water and white blood cells. Lymph fluid carries waste products from our cells and internal organs, and the white blood cells fight infections.

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.

The Lymphatic System

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, face, 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, several years or even over 20 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.



Stages of Lymphoedema

What are the symptoms of head and neck lymphoedema?

If you have head and neck lymphoedema, you may experience these symptoms:

- Changes in the appearance of your face, head and neck because of fluid building up
- Feelings of tightness, numbness, heaviness and warmth

If your head and neck lymphoedema is internal, you may also notice:

- Changes in your voice
- Difficulty swallowing
- Difficulty breathing
- Hearing difficulties

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:

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

Your lymphoedema specialist, will 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. You therapist may also provide you with a compression garment such as a special collar.

If necessary, your lymphoedema specialist may also recommend a special type of massage called **manual lymphatic drainage (MLD)**. MLD is used only until the swelling has gone down, which usually takes one to three weeks.

For more information on SLD and MLD, see page 16 and 22 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.

General Skin Care advice:

1. Keep your skin clean and dry but well moisturised. 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 on the neck folds.
2. Use a non-perfumed, low-pH moisturiser on your face, neck and chest daily. Use moisturiser from a pump or tube rather than a tub, which is more hygienic. Apply it before you go to bed at night.
3. If you shave use a well-maintained electric razor. Try not to 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. 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.
5. Protect your skin from the sun by wearing sun cream with a high sun protection factor (SPF 50). Never use a sunbed. Wear a hat when out in the sun.
6. 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:
 - **Wear insect repellent.**
 - **Be cautious when playing with your pets.**
7. Check your skin **daily** for cuts, scratches, burns, bites. Prevent infection by treating any damage immediately. Wash the area thoroughly, apply antiseptic cream and cover if necessary.
8. Pay special attention to your oral health. Make sure you brush your teeth as instructed. See page 11 for more information on oral health.
9. Treat any mouth ulcers, thrush or sore throats as recommended by your doctor/ nurse and stop any lymphatic drainage until your mouth/ throat heals.



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, 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>



Massage your Scar

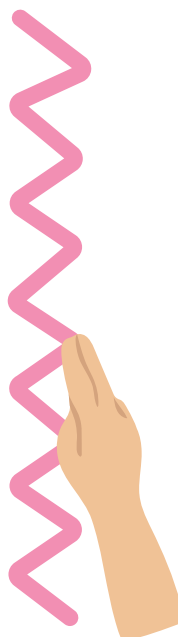
This massage is only if you have had surgery.

Do not massage until three weeks after surgery. Do not massage until all staples and clips have been removed.

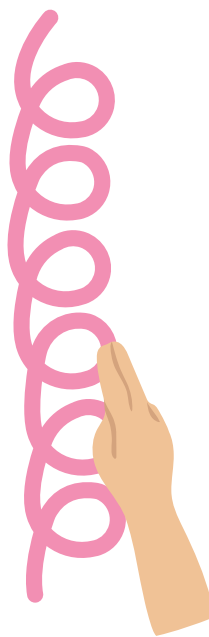
Your scar may feel very sensitive, tight or itchy. Scar massage will help reduce these feelings. This massage helps soften the scar and allows better blood flow to the area. You should not experience pain when massaging your scar.

- Place the palm of your hand over the scar
- Move up and down in a zigzag pattern or circle pattern along the scar (as to the right)
- Apply firm but gentle pressure whilst moving along the scar - try to move the skin, if possible lift the skin along the scar
- Repeat 5 times along the scar
- Now place your fingertips just above the scar and gently stretch the skin away from the scar and release. Repeat this action 5 times.
- Place your fingertips below the scar, gently stretching the skin away from the scar, and releasing. Repeat 5 times.

Zigzag Motion



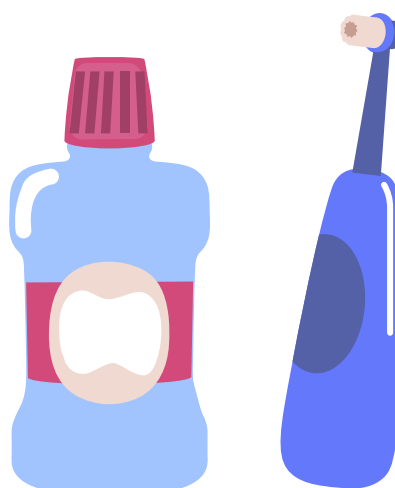
Circular Motion



Tip: Do not use oil or lotions while doing the scar massage. Apply any lotions or oils after the massage.

Oral Hygiene

- Keep your teeth, gums and mouth very clean, as this will help to control the soreness and reduce the risk of a mouth or throat infection.
- Brush your teeth regularly with a small, soft toothbrush and mild fluoride toothpaste, especially after meals and before bedtime. It may help to soften the brush in warm water before brushing.
- Use a mouthwash regularly if prescribed for you. Only use mouthwashes recommended by your dentist, radiation therapist or nurse. Some mouthwashes contain alcohol and are too harsh. You can also make your own using 1 teaspoon of baking soda (sodium bicarbonate) and 1 teaspoon of salt dissolved in 1 pint / half a litre of warm water.
- Avoid toothpicks
- If you have dentures, remove them every night and if your gums are sore.
- Take sips of fluids like water or milk often. Drink through a straw if your mouth is painful.
- Use a lip balm to keep your lips moist.
- Visit your dentist regularly. They can give you advice about caring for your mouth and special mouthwashes.



Exercise

Regular movement and exercise is important as the pumping of the muscles encourages the flow of fluid through the vessels, thus improving lymphatic drainage. Exercise also helps to maintain the movement in your facial muscles, neck and shoulders and prevents stiffness in the joints.

Exercise for movement

It is important to move your neck and shoulders following your operation in order to regain your full range of movement. You may find that these movements have become limited following your surgery and this is often due to swelling, discomfort, stitches, clips and the positioning of drains in your skin. Gentle exercises will help to regain your range of movement, help reduce swelling and prevent pain and stiffness in your shoulder and neck. You should continue with these exercises during your treatment and after it has finished, as agreed with your therapist.

Exercises for lymphoedema of the head and neck

Gentle rhythmical exercises that encourage movement and stretching can improve lymph drainage, joint movement and posture.

Posture

It is important to maintain a good posture. Avoid slouching when you are sitting down, and ensure you stand tall. It may be helpful to look at yourself in a mirror to ensure that your head and shoulders are in a good position. A good posture will help the movement of your shoulders and neck.

This is also very important when you are reading a book or looking at a lap top/ tablet/ phone. Make sure the device is at a suitable height that avoids a sustained neck bend.



Exercises for Lymphoedema of the Head and Neck

These exercises will help to improve the lymph flow. Repeat these exercises 10 times rhythmically at least three times a day.

If lying down, adjust pillows or bed so that your face is higher than your heart.

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.



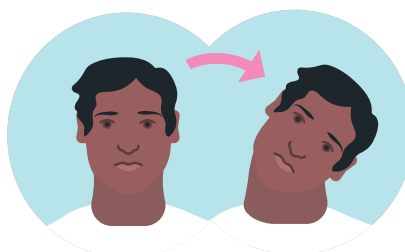
Exercise 2: Turns

- Stand tall, in front of a mirror if possible.
- Turn your head slowly from left to right, keeping your shoulders and back relaxed.
- Repeat 5 to 10 times.



Exercise 3: Tilts

- At first, it may help to stand before a mirror for this exercise. Looking forward, slowly tilt your head to one shoulder, keeping both shoulders still. Hold for at least two seconds.
- Return your head to the upright position and then tilt to the opposite shoulder. Hold for at least two seconds.
- Repeat 5 to 10 times.



Exercises for Lymphoedema of the Head and Neck

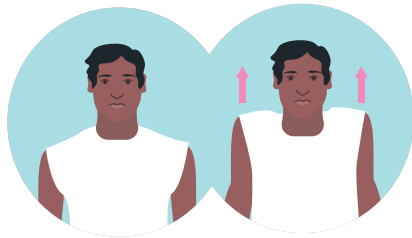
Exercise 4: Chin to Chest

- Standing upright, slowly move your head down so your chin touches your chest.
- Hold for 2 seconds.
- Return your head to its upright, forward looking position.
- Repeat 5 to 10 times



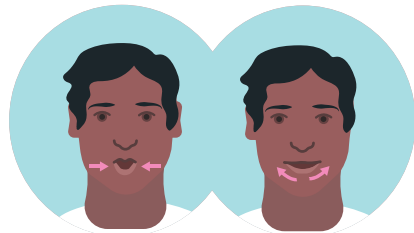
Exercise 5: Shoulders

- Standing tall and upright, bring your shoulders up to your ears, then let them drop, relaxed.
- Repeat 5 to 10 times.



Exercise 6: Mouth and Jaw

- Open and close your mouth repeatedly, like a fish.
- Pretend to blow out the candles on a birthday cake.
- Smile. Make it bigger than life.
- Speak the vowels a, e, i, o, and u out loud, in an exaggerated manner.
- Move your jaw from side to side.
- Without tilting your head, move your lower jaw forward. Return and repeat.



To Finish: Repeat exercise 1 - Breathing exercise



Top Tips to make the Most out of any Exercise

When can I return to normal activities?

Your scar should be healed about 6 weeks after surgery. You should also be able to move your neck and shoulders quite comfortably by then.

There are no set rules about when you should return to work, sports or hobbies. People heal differently, and some people have less energy than others. Start activities again slowly, and listen to your body.

- **Walking:** This is a good activity for maintaining or improving your health after an operation or radiotherapy. Taking short walks every day will help.
- **Driving:** Do not drive until you have full control of your vehicle. Only drive if you are well, alert and able to act quickly in an emergency. Check with your insurance company before you start driving, as you may not be covered if you start too soon.
- **Work:** When to return to work will depend on the type of job you do and whether you will be having any further treatment. Your surgeon, occupational therapist, physiotherapist or doctor will be able to give you advice on this.

Exercise

- Yoga and Pilates are 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. Some are specifically for cancer patients and survivors.

Sleeping

Using two or more pillows can help drain fluid back down towards your heart. You can also adjust your bed so your face is higher than your heart. If you always sleep on one side, that side might swell more. Try to change your position.

Self Lymphatic Drainage for Head and Neck

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.

There is a link to videos to demonstrate SLD in 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.
- 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.
- You can incorporate this with your scar massage.



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: 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 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, inwards and upwards and release.
- Repeat 5 times.



Step 4: 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.

Self Lymphatic Drainage for Head and Neck



Step 5: Neck to Armpit

- Place your hand on your collarbone. Move your hand down toward your underarm. This massage will move the lymph fluid from your neck and chest to your underarm lymph nodes.
- Gently stretch the skin (not muscles) down your chest and towards your underarm. Then let go of the skin.
- Repeat this massage 10 - 15 times.



Step 6: Face

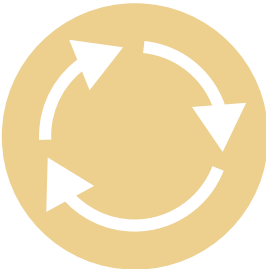
- Stroke above and below your lips finishing in front of your ears where your side burns are.
- Stroke from bridge of nose outwards across your cheeks finishing in front of your ears. Start at the tip of your nose.
- As above working upwards towards your eyes, being careful not to press too hard around the eye area.





Step 6: Face - Continued

- Lightly pinch the eyebrows, starting from the inner brow moving outwards to the outer eyebrows to facilitate lymphatic drainage towards the peri-auricular lymph nodes in front of your ears.
- Stretch the skin from the outer forehead, working down to your side burns.



Step 7: Repeat

- Repeat steps 5, 4, 3, and 2 in sequence.



Step 8: 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.

Compression garments

Compression garments may be provided to help improve your swelling. Please follow the instructions provided by your Lymphoedema therapist. Compression garments need to be washed regularly, and will be reviewed for replacement as required.

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 **important** in controlling your lymphoedema.

Tips on wearing your compression garment

- Do not put your garment on immediately after a shower or bath as it's difficult when your skin is damp.
- Ensure the garment has no wrinkles and fits smoothly. Lymphoedema specialist for advice.
- Moisturise your skin at least a half hour before applying your garment as the moisturising lotion can affect the fibres in your garment. Wipe off any excess moisturiser from your skin before applying it.
- It is important to wear your compression garment during the day but you can take wear it at night if it helps to keep the internal fluid from building up.
- Always exercise with your garment on. Muscle movement against the garment will encourage lymph drainage.
- You may 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

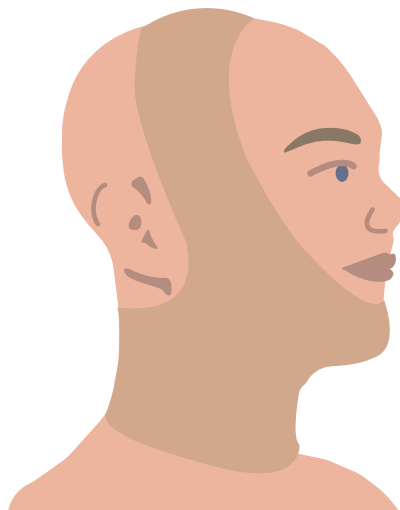
- Have creases or wrinkles in the garment.
- Fold over the ends of the garment, as this will restrict the blood flow and cause more swelling.
- Cut or alter the garment.

Remove your garment and tell your Lymphoedema specialist if:

- You have 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 on your head or neck

Kinesio tape

Your lymphoedema therapist may decide to use Kinesiotape to help reduce the swelling.



Complex Decongestive Therapy

What is Manual Lymphatic Drainage?

MLD is a very gentle form of massage and is a key part of which aims to move fluid away from swollen areas by increasing normal lymphatic activity and bypassing lymph vessels that don't work well. MLD is only effective when compression is applied directly afterwards and exercise.

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.
- 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.

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.

General advice

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.



Compression Garment Tracker

Compression Garment Tracker

Useful Organisations and Websites

HSE Lymphoedema Information

www.hse.ie/lymphoedema

Europa Donna

www.europadonnaireland.ie

Lymphoedema Ireland

www.lymphireland.com

Lymphoedema Network

Northern Ireland (LNNI)

www.lnni.org

The Lymphoedema Support

Network (LSN)

www.lymphoedema.org/lsn

The British Lymphology Society

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

Videos about lymphoedema

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



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