

National Lymphodema Services

# Risk of Head & Neck Lymphoedema

after treatment for cancer













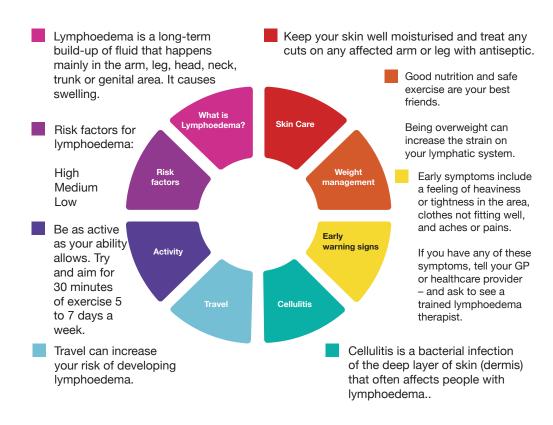
Lymphoedema (pronounced lim-fo-dee-ma) can happen when surgery or radiation is used to treat cancer. The surgery or treatment may cause a build-up of fluid in your body that results in swelling. It happens because your lymph nodes have been removed or blocked, or because they have been damaged by radiation. It can occur in your arm, leg, head, neck, trunk or genital area. Which area is affected depends on where you had surgery or radiation.

The fact sheets will help you to work out your risk of developing lymphoedema. It will show you ways of helping the rest of your lymph nodes to do their job of draining lymphatic fluid in your body and carrying out its other important functions.

Lymphoedema can develop at any stage after your cancer treatment, but the risk of having it is highest in the first one to three years after treatment ends.

If lymphoedema is detected early, it is easier to manage and may be reversed.

#### Overview of lymphoedema and risk reduction;



Lymphoedema is when too much fluid builds up in your body. It is caused by your lymphatic system not working properly.

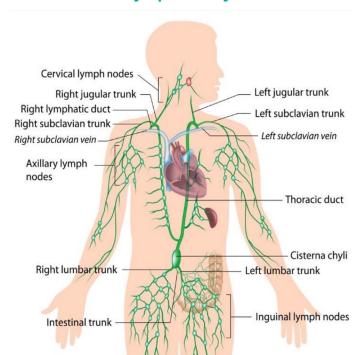
Your lymphatic system can be damaged if your lymph nodes have been removed or affected by radiation during treatment for cancer.

Lymphoedema can happen at the site where you have had surgery or radiation. It can also happen in your arms, legs, trunk, head, neck or genital area.

Your lymphatic system is important because it:

- Maintains the fluid balance in your body
- Monitors and runs the main waste disposal system for your cells and internal organs
- Transports fats, absorbing some fats from your digestive organs and transporting them into your bloodstream where they can be processed
- Monitors and runs your immune response the lymph nodes are like a filtering plant, sifting the waste for any signs of virus or bacteria and setting up a battle against any invaders (this is why you get swollen lymph nodes when you have an infection)

## The Lymphatic System





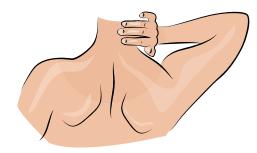
If you have had treatment for head or neck cancer, lymphoedema can happen in any part of your head, neck or face. There are a large number of lymph nodes in these areas.

Lymphoedema can happen after cancer treatment because parts of your lymphatic system have been removed or harmed by surgery or radiation. Also, scar tissue from these treatments can change how your lymph system works.

Swelling from surgery normally goes away quite quickly. But if it lasts more than 6 weeks, you may need treatment to bring it down.

Lymphoedema can occur after treatment and can happen inside your mouth or airway or on the outside your head, neck or face.

• Internal lymphoedema can happen anywhere inside your body, such as your mouth, tongue, larynx (voice box), airway and throat. • External lymphoedema can happen in your neck and face and can affect your lips, nose, eyelids and ears. You can have either internal or external lymphedema, or both.



If you experience any of these symptoms, please discuss them with your doctor, nurse or physio and ask to be referred to a lymphoedema therapist.

## Early signs of head and neck lymphoedema

- Swelling in any part of your head and neck that may feel hard to the touch
- · A feeling of tightness in your skin or muscles
- · A restricted range of motion in your neck which is not improving after surgery
- Changes in your sight or hearing
- · A change in breathing, swallowing, eating or speaking
- Feeling congested (stuffy nose)
- · Pain in your ear

Do not start your neck exercises until your scar is fully healed. Slowly increase repetitions when you are able to.

It's normal to feel your muscles and tendons stretching during the exercises. This sensation should stop soon after the exercise ends.

Perform these exercises with caution during radiotherapy and stop if you have problems with your skin. If you feel pain or stiffness in your neck and shoulder, ask your surgeon or GP for a referral for an appointment with your treating hospital's physiotherapy department.

#### 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.

#### 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

### 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.
- Repeat each of these activities 5 to 10 times.

#### **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.

#### **Shoulders**

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

Adjust pillows or bed so that your face is higher than your heart. Gentle, exercises, such as those in a "gentle yoga" class, may improve your mobility, reduce pain and help instil a sense of calm.



## Physical activity and exercise

Exercise is essential for your lymphatic system. It works your muscles, and this increases the flow of lymph fluid away from any swollen areas. Try to introduce deep breathing into your daily routine because it improves circulation and gets your lymph fluid flowing.

Be as active as you can. Try to aim for 30 minutes of exercise 5 to 7 days a week. Begin slowly and build up gradually. Find activities that you enjoy. It is important to gradually increase your exercises after your treatment or surgery. Listen to your body and take one day at a time.

Exercise will make you feel less tired during treatment and after surgery. Exercise will also help to improve your sense of wellbeing.

Ask your physiotherapist for specific arm and leg exercises you can start after your treatment or surgery. Tell them immediately if you notice any swelling in your arm or leg.

### Types of physical activity

Physical activity can be 'planned' or 'unplanned'.

- 'Planned activities' include things such as going for a walk, dancing, running, cycling, yoga, football and swimming.
- 'Unplanned activity' includes doing things like housework, playing with children or grandchildren and general day-to-day tasks.
- Physical activity can be enjoyed alone, with family or as part of a group.
- Moving more can have important health benefits. Any activity is better than none!
- Setting goals can help you to become more active and to continue with your physical



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Week 1	5-10 min of brisk walking, daily
Week 2	10-15 min of brisk walking, daily
Week 3	15-20 min of brisk walking, daily
Week 4	20-25 min of brisk walking, daily
Week 5	25-30 min of brisk walking, daily
Week 6	30 min of brisk walking, daily













### Create your own goals diary

This is a goal-setting log or diary you can copy. Use it to keep track of your progress every week.

Consistently tracking your activity will help keep you accountable. Some days you might be able to do more than others. Any activity or movement will help to prevent and treat lymphoedema

Ask your physiotherapist for specific arm and leg exercises you can start after your treatment or surgery. Tell them immediately if you notice any swelling in your arm or leg.

#### Week 1

Goal:

Day	Activity	Minutes	Total
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			

#### Practical tips for starting a new activity

Try the activity – Try doing a small amount of light activity and then rest a little. Find the level which is manageable for you – you may be more tired or have more pain the day after doing an activity so wait to see the result.

Rest – As you exercise and increase your level of physical activity, your body needs rest to cope with the increase in activity. It is important to alternate days between a physical activity day and rest day. This will help promote recovery as well as increase your overall function.

Slowly increase activity – Often people try and increase their activity levels too quickly, so if in doubt go more slowly but steadily. Slow increases in activity is important for preventing setbacks to your recovery. Going slowly will help your body to adapt to the increase in activity.

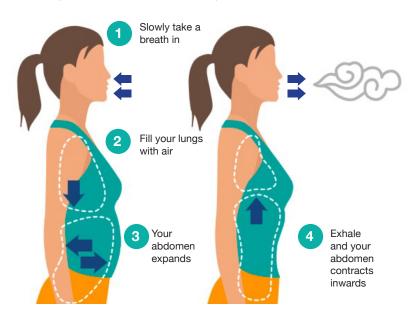
**Fun** – Don't forget to incorporate fun into your exercises. Get creative in ways to add physical activity to your daily routine. Include family and friends into your physical activity and rehab journey.



Breathing exercises and good posture are key to keeping your lymphatic flow even.

#### **Deep breathing exercises**

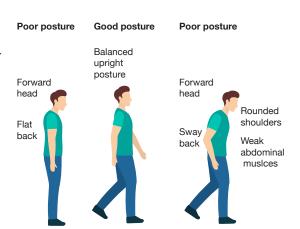
(Try to do 2 to 3 deep breathes 2 or 3 times a day.)



#### **Posture**

Immediately after surgery it may be painful to adopt an upright posture. Do your best to achieve this a few days after your surgery.

- Stand or sit tall.
- Leave your arms by your side.
- · Relax your shoulders.
- Bring your shoulder blades together at the back. Try correcting your posture while breathing in for 5 seconds and out for 10 seconds initially.





## Take care of your body

If you're at a healthy weight now, work to stay that way. Good nutrition and safe exercise are very important.

Excess weight can increase the strain on your lymphatic system. It also increases your risk of lymphoedema.

Body mass index (BMI) is a term used to describe the state of your health related to height and weight. Having a BMI over 30 can increase your risk of lymphoedema. A healthy diet and movement are key to reducing your BMI. See the section on exercise for more information and use this website to calculate your BMI:

www.safefoodnet/bmi- calculator

### **Healthy diet**

Reducing protein in your diet will not prevent lymphoedema. Protein is essential for keeping your body healthy and fully functional.

There is no special diet that will control lymphoedema. You should eat a well-balanced diet that includes vegetables and fruit.

You should lower your intake of salt because salt makes your body retain fluid, which can increase your swelling. For more information on healthy eating see links below or consult a dietician.

### **Healthy eating**

https://www.safefood.net/healthy-eating

## **Eating well**

https://www.gov.ie/en/publication/e15e3-eating-well/



### **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. Instead, the lymph nodes will attract more fluid from other parts of your body and will increase the swelling.

You should reduce your intake of alcohol and drinks with caffeine, such as tea and coffee.

Diuretics — also known as water pills. Avoid diuretics and don't take them unless they have been prescribed by your doctor for another medical condition. Diuretics are not effective in the treatment of lymphoedema.

There are many fad diets and myths about healthy eating and lymphoedema.

If in doubt, talk to your GP or dietician about what's right for you.

## Useful tips to reduce your risk of developing lymphoedema

Be careful in the sun. Use sun protection with SPF 50 outdoors.

- Try to avoid excessively hot or cold baths and showers as this increases the likelihood of swelling.
- Use natural skincare products where possible with low pH.
- Cellulitis is an infection of the skin. Be alert to it as infection can increase your risk of developing lymphoedema. Symptom include:
- Fever
- Swelling
- · Redness
- Pain
- · High temperature

If you get any of these symptoms in your affected arm, leg, breast or head and neck consult your GP (family doctor).

See the section on cellulitis for more information.

## Taking care of your scar

Scars are normal after surgery but they can become tight and uncomfortable. Gentle stretches and movement will help scars to feel less tight. Gentle massage will also help after the scar is fully healed, which is normally 4 to 6 weeks after your surgery. It also helps to use moisturisers on the scar to help soften the area after a massage.

If your scar is causing pain or limiting your movement ask to be referred to a physiotherapist.





## Taking care of your skin

Open skin can act as an entry point for Infection.

- Avoid getting cuts, scratches and burns by using oven gloves and gardening gloves. Have antiseptic cream and a basic first aid kit on hand just in case.
- Consider using an electric razor rather than a bladed razor for hair removal and take care not to cut your cuticles when cutting your nails.
- If possible, avoid injections or blood tests on the affected arm or leg.
- If possible, have your blood pressure taken on the opposite arm to the one with lymphoedema.
- Do not wear tight jewellery or clothing that causes marks or indentations on your skin on the affected side.

If you must have an injection in an at-risk arm or leg, use antiseptic and watch for signs of infection in the following days.

If both of your arms or legs are at risk, then discuss it with your oncology team or lymphoedema therapist to decide if using an at-risk limb is a reasonable option or not.

#### **Acupuncture**

There is no evidence that acupuncture causes lymphoedema but needle insertion does break the skin barrier. Ask your acupuncturist if they can use a different arm or leg to create the same acupuncture effects.



## Travel tips for reducing your risk of lymphoedema

Some people have reported swelling of the arm or leg (lymphoedema) after air travel and long car, bus or train trips. There is no conclusive evidence that the trip itself causes lymphoedema, but there are a number of theories about why travel may cause lymphoedema.

Here are some of the reasons:

- Lymphoedema may be triggered by the combination of low cabin pressure and physical inactivity when flying.
- Any long trip can involve long periods of physical inactivity, which may reduce lymphatic flow and cause your arm or leg to swell.

Lymphoedema may be triggered by extra activities as you prepare to travel or by changes in normal routine, such as:

Concentrated cleaning of the house before the trip (like vacuuming or ironing) can place extra strain on the lymphatic system of a limb

- · Carrying heavy luggage
- Juggling luggage with a heavy shoulder bag
- Stopping normal exercise routines while on holidays

## Ways to reduce your risk of lymphoedema

- Spread the cleaning of the house over several days – or better still, get someone else to do it.
- 2. Consider using luggage on wheels.
- Try to carry your shoulder bag on the opposite shoulder to the side where you had surgery.
- 4. Exercise your arms and legs during the trip. Consider taking a soft squeeze ball and use it regularly.
- Walk about every couple of hours. It's good for the back as well as your general lymphatic flow.
- Air travellers should wear loose-fitting, non-restrictive clothes.
- 7. Stay well hydrated and avoid alcohol and drinks with caffeine.
- 8. If you are travelling by air, try to get a seat that allows you to move about.
- If you are travelling by car, bus or train, exercise your arm or leg as much as possible.
- 10.If you are driving, shift your arm around and keep the lymphatic flow moving by gently squeezing the steering wheel.





### What is cellulitis?

Cellulitis is an acute spreading inflammation of the skin and subcutaneous tissues. It causes pain, warmth, swelling and redness. Most episodes of cellulitis are believed to be caused by the bacteria Streptococci.

#### What causes cellulitis?

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

## How do I know if I have cellulitis?

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 first, as if you are coming down with flu, but not always. Symptoms may include fever, shivers, muscular aches and pains, headache, nausea and vomiting.

## Why can cellulitis lead to lymphoedema?

The relationship between cellulitis and lymphoedema appears to be a vicious cycle:

People with cellulitis are at risk of developing lymphoedema and people with lymphoedema are at high risk of developing cellulitis. So it can become a vicious cycle.



## How can I reduce the risk of developing cellulitis?

It is essential to look after your skin and try and avoid cracks, cuts and open areas. Regularly check your skin on any area affected by lymphoedema and if you have a cut, apply antiseptic. If a cut looks like it is not healing, contact your GP. Try to avoid injury by using oven gloves, gardening gloves and nail clippers rather than scissors for cutting your fingernails and toenails.

For more information, please see the skin care section.

## What to do if you think you have cellulitis

Contact your doctor immediately because you will need to take a course of antibiotics. Treating cellulitis is very important when you have lymphoedema because you may become very ill, and also because of the danger that your lymph drainage routes may be damaged further.

If you have lymphoedema, it is important to:

- Remove any compression garments that are pressing on the affected limb until it feels better. Start using the limb or affected part again as soon as you can.
- Stop other forms of treatment such as manual lymphatic drainage and exercise programmes while you are being treated for cellulitis.
- Rest with the affected limb elevated to a comfortable position – ideally raised to the same level as your heart.
- · Drink plenty of water.
- You can take paracetamol but avoid anti-inflammatory medications such as ibuprofen.



- If you are familiar with cellulitis attacks and have appropriate oral antibiotics to hand, you should start taking them immediately and finish the course completely even if symptoms improve.
- You can find useful information at www.thebls.com/documents- library/ consensus-document-on-themanagement-of-cellulitis-in-lymphoedema

If you suspect you are developing lymphoedema please call:









