



Reducing the Risk of Developing

Head/Neck Lymphoedema Advice Sheet

The information and advice within this leaflet will help you reduce the risk of developing lymphoedema. You should keep this sheet in a safe place as it also includes a self-referral form.

What is lymphoedema?

Lymphoedema is a persistent swelling of any part of the body but is more commonly seen in the arms and the legs. This swelling is a collection of fluid within the tissues under the skin, which cannot be drained by a needle. This fluid, known as lymph, is colourless and odourless but is rich in protein. This high protein can cause dryness of the skin. There is no cure to lymphoedema, but once diagnosed, it is manageable.

Why are you at risk of developing lymphoedema?

This may be because you have recently had surgery or treatment where the lymph nodes in your lymphatic system have been removed or treated with radiotherapy. Damage to the lymphatic system alters normal lymphatic drainage and flow. The risk of lymphoedema does increase if you have had all your lymph nodes removed and you have had radiotherapy. It also increased if you are overweight and/or have repeated skin (cellulitis) or wound infections. Lymphoedema can occur at any time even many years after your surgery or radiotherapy.

If I have lymphoedema, what symptoms can I expect?

Often after surgery inflammation occurs and is a natural response to healing, however **if the swelling does not improve after 3 months** then this could be lymphoedema. You may find that your jewellery or clothing may feel tighter than usual.

You may find that your face, neck and chest may feel heavy and give you some discomfort. Tightness of the skin can also be an early symptom. Similarly, weight gain can also cause related symptoms to lymphoedema.

How can I reduce my risk?

There is a lot you can do to try to reduce the risk of lymphoedema occurring. It must be considered though that some people will get lymphoedema whatever they do and this may be due to your genetics. The following suggestions are based on what you can do:

1. Weight Management

Being overweight or gaining weight **is the biggest risk factor in developing lymphoedema**. In order to reduce your risk of lymphoedema it is important to maintain a good healthy diet. If you are unsure what a 'normal' weight for you should be, ask a health care professional or look at some NHS Better Health/ Lose Weight websites.

2. Movement and Exercise

Gentle movement, exercise and activities will help the muscles pump lymph fluid more effectively through your body. Movement helps you improve and maintain flexibility and keeps your bones strong. Being active can help you achieve and maintain a healthy weight and may improve your emotional wellbeing.



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Activities such as walking on the spot or going for a walk are ideal, as are swimming, cycling, bowling, gardening, housework and even shopping. Basically, move your body more. If your mobility is limited, you can still move your body. Pacing yourself is important. Set yourself personal and achievable goals. Sometimes keeping a record of how much activity you do can be beneficial.

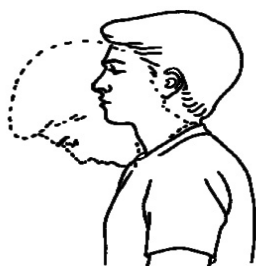
Try to do a little every day and build up to about 30 minutes of activity / exercise, 5 days a week. If you are used to exercising, it is a good idea to go back to what you had been doing - BUT start gradually and build up on a day-to-day basis. If you go to a gym or exercise class, remember to listen to your body. Discuss your condition with your instructor so that they can adapt the quantity or intensity of exercise you do if necessary.

Breathing exercises are also shown to be important in improving lymphatic drainage. Singing and laughing yoga can be helpful.

Exercises to Encourage Lymph Drainage

Exercises should be performed 3 times a day.

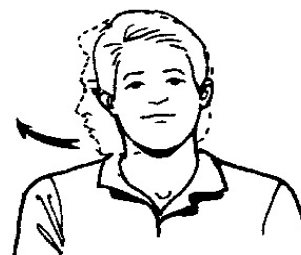
Repeat each exercise 5 times.



Gently tilt your head down moving your chin towards your chest.



Gently tilt your head back as if you are looking up at the ceiling.



Slowly turn your head to one side as far as you are able and then repeat the other way.



Slowly tilt your head towards your shoulder as if you are trying to put your ear on your shoulder and repeat on the other side.



Roll your shoulders backwards.

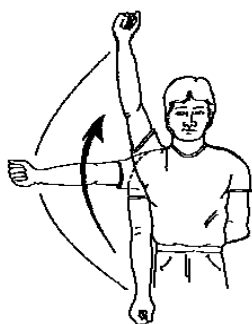
Roll your shoulders forwards.



Raise your arms overhead as far as you can and slowly bring them back down.



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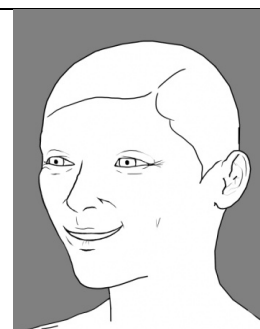
Raise your arms out to the side as far as you can and slowly bring them back down.



Slowly scrunch up your eyes and feel your face tightening. Hold and relax.



Purse lips together and push outwards as if you're going to kiss someone. Hold and relax.



Give a really big smile. Feel the tension and then relax.

Simple Lymphatic Drainage (SLD)

This is a very simple massage technique that is used to stimulate the undamaged lymphatic nodes and vessels. This encourages the lymphatics to work more efficiently and effectively, directing the flow of lymph from the affected area towards the healthy lymph nodes.

The massage technique should be practiced at least once a day and should take you around 10-15 minutes.

The massage should be performed slowly and gently. You do not need to use oil or cream, but if your hands feel sticky then talc or cornflour can be used. If there is any redness on your skin, your pressure is too heavy.

The massage technique should be applied when you are either sitting comfortably or lying down. Do not rush the massage.

Please note, do not perform SLD during radiotherapy. Commence SLD 6 weeks after your radiotherapy has finished.

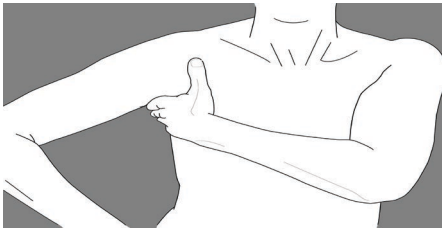
The following steps are for swelling on both sides of your head, face and/or neck. Follow the steps in order:

Step 1



The start of SLD is very important and involves abdominal breathing.

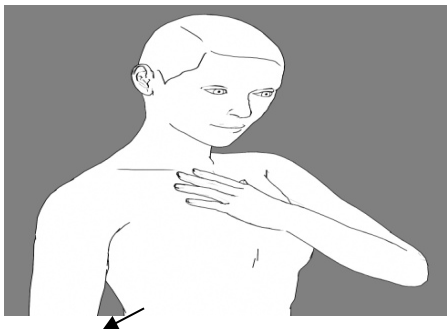
- Place both hands on your stomach. Breathe in and feel your stomach rising (imagine a balloon inflating under your hands)
- Slowly breathe out and press gently inwards with your hands
- Repeat 3 times.

**Step 2**

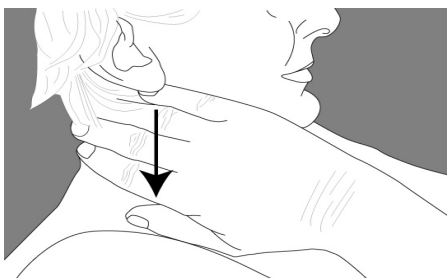
- Place your hand in your armpit
- Massage upwards into your armpit and release
- Repeat 10 times on both sides

Step 3

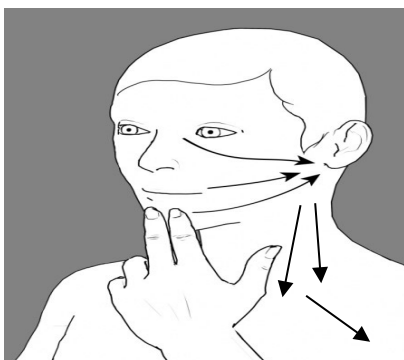
- Place your index finger above your collarbone and your middle finger below your collarbone, so that your collarbone lies between these two fingers
- Gently push downwards and release
- Repeat 10 times on both sides

Step 4

- Using the flat part of your fingers, gently stroke downwards from your RIGHT collarbone to your right armpit. Now repeat on LEFT side.
- Repeat 10 times on both sides

Step 5

- Place your hands on either side of your neck below your ears
- Gently stroke down towards to your armpits.
- Repeat 10 times on both sides

Step 6

- Start at your chin and gently stroke your skin towards your ears and then down your neck towards your armpit
- Repeat 10 times
- Repeat across your face, starting next to your mouth and stroke towards your ears and then down the neck
- Repeat at nose level
- Repeat both sides



3. Look after your skin

Skin care is important, because it helps reduce the risk of infection, which may trigger the development of lymphoedema.

- Wash your skin daily with warm water and soap.
- Dry your skin thoroughly especially between skin creases / folds.
- Apply moisturising cream to your skin to prevent it from dryness.
- Prevent sunburn by using a high factor sun cream.
- Use insect repellent if prone to bites.
- Use clean razors as rusty blades can cause nicks.
- Daily skin care will help you to reduce your risk of infections, such as cellulitis.

What is a cellulitis Infection?

Cellulitis can start as a rash or your skin becomes red, hot to touch, and may be tender or painful. You may develop swelling and you may feel generally unwell as if you have the flu.

If you think you have an infection, seek medical help immediately from your GP. If you notice these symptoms out of hours, contact your out of hours GP service. It is important to act quickly to prevent the infection from getting any worse. You will need antibiotics as soon as symptoms occur and if you have lymphoedema you might need to take them for two weeks. You should always take the full dose of the antibiotics as prescribed.

What should I do if I have a cut or scratch my skin?

Any trauma or injury to your skin could increase your risk of infection and developing swelling.

Treat all cuts, grazes, burns and bites with the following steps:

1. Clean the area well with water
2. Use an antiseptic solution or cream if possible
3. Cover with a sterile dressing or plaster if necessary

You only need antibiotics if you have any of the symptoms of a cellulitis infection. If in doubt, seek medical advice.

Scars and skin care

Following surgery or trauma, you may have scars that could affect your lymphatic system. All scars look different during the healing phase. It is important that you clean your scar and touch the surrounding skin every day. Once your scar has healed, use a lanolin-free cream or oil and gently rub this into your scar in a circular motion.

Numbness, pins and needles, hypersensitivity, and stabbing pains are all different forms of nerve irritation that can happen following surgery. Cord-like structures (cording) can cause restriction of movement up to six-month post-surgery. Sometimes these cords can 'snap' naturally, during activity – there is no need to be worried or alarmed if this does happen. Massage and exercise can really help with relieving these symptoms.



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4. Dispelling the myths about risk reduction

Research used to suggest that you had to avoid needle-stick procedures such as blood tests, immunisations, acupuncture and tattoos as this could damage your skin and could cause a cellulitis infection. Newer evidence suggests that needle stick procedures are safe as long as they are performed aseptically.

Lymphoedema Wales Clinical Network suggest you offer your unaffected side if possible, however if this is not an option or if you have to have tests done then you should not worry. Please contact your local Lymphoedema Service for advice.

Having your blood pressure taken on your at risk arm was also thought to increase the risk of lymphoedema developing. Recent evidence has shown this not to be true, however you may decide to still use your unaffected side, as the pressure cuff can be painful when inflated. You do not need a compression sleeve to go on the aeroplane / fly either.

There is also **no evidence** to suggest that you should avoid:

- Using saunas or hot tubs.
- Having complementary therapies.
- Carrying weights or your handbag on your at risk shoulder.
- Repetitive movements.

What should I do if I think I have lymphoedema?

It is important to contact your specialist team or your GP for advice and please complete the self-referral form at the end of this leaflet (either post or email to your local lymphoedema clinic). It is important you continue to follow the advice in this leaflet while you are waiting for an appointment to be seen.

Patient Story

Rob was diagnosed with head & neck cancer and had surgery and radiotherapy. Immediately after surgery, their face and neck was swollen, but gradually this reduced. However, after treatment Rob's skin became firm and swelling appeared under his chin. Rob returned to performing his head and neck exercises and skin care regime daily, and started his drainage routine six weeks after radiotherapy. This softened his skin and improved his swelling immediately. Rob continues with this self-management, because he feels it reduces the stiffness in his neck and keeps his skin and tissues soft.

What could Rob have done differently? Rob could have continued with skin care regime, and head and neck exercises instead of stopping four weeks post-surgery.

Follow the link or QR code to view some short videos about lymphoedema and ways to help you manage at home: www.medic.video/w-lymph





Lymphoedema Wales Clinical Network Self-Referral Form

Please complete all sections where possible, using CAPITALS or typed font

Patient Information		
1	Title & Full Name	
	Date of Birth	
	NHS Number	
	Address	
	Telephone	
	Email	
	Preferred Language	<input type="checkbox"/> Welsh <input type="checkbox"/> English

GP Details		
2	GP Name	
	Telephone	
	Email	
	Surgery Address	

Lymphoedema History	
Please tick area(s) of swelling	Duration of swelling
	Current problem/ reason for referral
	Does the patient have any wounds?
	<input type="checkbox"/> Yes (specify) <input type="checkbox"/> No
	Does the patient have lymphorrhoea (leaking)?
	<input type="checkbox"/> Yes <input type="checkbox"/> No
	Is the patient currently in compression bandages?
	<input type="checkbox"/> Yes (specify) <input type="checkbox"/> No
	Who is involved with their care?
	<input type="checkbox"/> District Nurse <input type="checkbox"/> Leg Club <input type="checkbox"/> Wound Clinic <input type="checkbox"/> Podiatry <input type="checkbox"/> Practice Nurse <input type="checkbox"/> Dermatology <input type="checkbox"/> Other (specify)
	Has the patient had 2+ episodes of cellulitis in the last year?
<input type="checkbox"/> Yes <input type="checkbox"/> No	


Body Mass Index			
4	Underweight / normal - <18.5 -24.9		Obese Class III 40-49.9
	Pre obese 25-29.9		Obese Class IV 50-59.9
	Obese I-II 30-39.9		Obese V 60>



Medical History <i>(Please also attach GP patient summary if available. Use space to comment if necessary)</i>					
5	Cardiac	<input type="checkbox"/> Yes <input type="checkbox"/> No			
	Vascular/Arterial Disease	<input type="checkbox"/> Yes <input type="checkbox"/> No			
	Diabetes	<input type="checkbox"/> Yes <input type="checkbox"/> No			
	Skin Conditions	<input type="checkbox"/> Yes <input type="checkbox"/> No			
	Mental Health Diagnosis	<input type="checkbox"/> Yes <input type="checkbox"/> No			
	Dementia	<input type="checkbox"/> Yes <input type="checkbox"/> No			
	Learning Difficulty	<input type="checkbox"/> Yes <input type="checkbox"/> No			
	Mobility Restrictions (specify)	<input type="checkbox"/> Yes <input type="checkbox"/> No			
	Cancer History (specify)	<input type="checkbox"/> Yes <input type="checkbox"/> No			
	Lymph Node Surgery	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Clearance	<input type="checkbox"/> Sampling	<input type="checkbox"/> SLNB
	Radiotherapy:	<input type="checkbox"/> Yes <input type="checkbox"/> No			
	Chemotherapy:	<input type="checkbox"/> Yes <input type="checkbox"/> No			
	Other (specify)	<input type="checkbox"/> Yes <input type="checkbox"/> No			

Medication <i>(please attach GP medication record)</i>	
6	

Referrer Details	
7	Full Name and Role
	Telephone/Mobile
	Email
	Referral Date (DD/MM/YYYY)

Additional Information <i>(if required)</i>	Education Films
8	Visit www.medic.video/w-lymph and www.medic.video/w-lymph-edu or use the QR code. 

Health Board Lymphoedema Services	
9	Aneurin Bevan University Health Board: Lymphoedema Department, Springfield Day Unit, St Woolos Hospital, Newport NP20 4SZ: Tel: 01633 238464 lymphadmin.abb@wales.nhs.uk
	Betsi Cadwaladr University Health Board: Lymphoedema Clinic, Department 20, Wrexham Maelor Hospital, Croesnewydd Road, Wrexham LL13 7TD Tel: 01978 726257 lymphoedema.services@wales.nhs.uk
	Cardiff and Vale University Health Board: Lymphoedema Clinic, Cardiff Royal Infirmary, Glossop Road, Cardiff CF24 0SZ: Tel: 029 2033 5280 lymphoedema.CAV@wales.nhs.uk
	Cwm Taf Morgannwg University Health Board: Lymphoedema Clinic, Dewi Sant Hospital, Albert Road, Pontypridd CF37 1LB: Tel: 01443 443499 CTM_Lymphoedema@wales.nhs.uk
	Hywel Dda University Health Board: Lymphoedema Department, Ty Geraint, Bronglais Hospital, Aberystwyth, Ceredigion SY23 1ER Tel: 01970 628852 lymphoedema.hdd@wales.nhs.uk
	Powys Teaching Health Board: Lymphoedema Clinic, Bracken Trust, Cefnlllys Lane, Llandrindod Wells LD1 5LJ: Tel: 01597 825152 powys.lymphoedema@wales.nhs.uk
	Swansea Bay University Health Board: Lymphoedema Clinic, Singleton Hospital, Swansea, SA2 8QA Tel: 01792 285252 lymphoedema.clinic@wales.nhs.uk
10	OFFICE USE ONLY <input type="checkbox"/> Standard <input type="checkbox"/> Non-standard <input type="checkbox"/> Reducing the risk