



Advice and General Information on Lymphoedema after Assessment

Lymphoedema Wales Clinical Network has dedicated Lymphoedema Services in all of the seven Health Boards in Wales. As a patient of this service you will have been assessed, diagnosed and offered treatment based upon your clinical needs and what is valuable to you. This may include follow up appointments, intensive treatment and ongoing support to help you manage your condition. Appointments may be face to face or in a virtual way using audio-visual technology or telephones. As lymphoedema can be lifelong, it is important that we work together to help you manage your swelling as independently as possible. Value-Based Healthcare is embedded in Lymphoedema Wales Clinical Network. This means that you as a patient will work in partnership with your therapist to manage your lymphoedema successfully and that we consider what is really important to you. One of the ways we capture what is important to you is by asking you to complete a Patient Reported Outcome Measure (PROM). PROMs are questions about how lymphoedema affects your life. In Wales we use a PROM called LYMPROM[®]. Many of the Health Boards in Wales use a digital method to capture PROMS using a link sent to your phone or an email. Paper versions are also available should you prefer this.

What is Lymphoedema?

Lymphoedema is a persistent swelling of any part of the body. It is most commonly seen in the arms and the legs. This swelling is a collection of fluid within the tissues under the skin that cannot be drained by a needle. The fluid, known as lymph, is colourless, odourless but is rich in protein. High protein in the tissues can cause dryness of the skin, and if untreated may create some complications such as leaking fluid, ulcers, wounds and cellulitis (skin infection). Currently, there are over 25,000 people in Wales that have lymphoedema and have been seen in the last year. In the UK they estimate over 400,000 people have lymphoedema. The risk of lymphoedema developing increases in the older population as well as in the obese and less active.

The lymphatic system works closely with the circulatory system. It drains fluid via lymph nodes and vessels back to the heart and kidneys. Lymph nodes can be thought of as recycling stations - all the fluid is checked for infections so that the body's defence mechanism can be alerted. Thus, the lymphatic system plays an important role in preventing and fighting infection, removing dead or abnormal cells and excess proteins. There are two types of lymphoedema: primary and secondary.

Primary Lymphoedema is due to a problem with the development of the lymphatic system. It can be present at birth, develop in early childhood, or early adulthood. In some cases, it can be hereditary and there is ongoing research into genetic links.

Secondary Lymphoedema is caused by damage to the lymphatic system. Surgery, radiotherapy, cancer, vein problems, trauma, some skin conditions including repeated cellulitis (skin infection), immobility and obesity can all cause lymphoedema to occur. In tropical regions it can also be caused by a parasite called Filarisis; this is extremely rare in the UK.

It is possible to reduce the amount of lymphoedema present if the swelling is identified early and treatment is followed. For the majority of people, lymphoedema is a lifelong condition. There is no cure for lymphoedema, but following your treatment plan will help. Only a very small proportion of people with lymphoedema may be suitable for super micro-surgery or liposuction which may help. If your therapist thinks this could be suitable, they will discuss this with you.

Management of Lymphoedema

If you have been assessed and diagnosed with lymphoedema, it is important to manage your condition by following the treatment plan.

1. Skin Care

Skin care is very important to the management of your lymphoedema as it reduces the risk of having a cellulitis which in turn causes more damage to the lymphatic system. Things to do to take care of your skin include:

- Wash your skin daily with warm water and soap/soap substitute
- Dry your skin thoroughly especially between the fingers and toes to avoid getting a fungal infection
- Apply moisturising cream to your skin to prevent it from drying and cracking. Creams or lotions are ok
- Jointly, you and your therapist will decide which soaps and creams are best for you
- Daily skin care will help you to reduce your risk of cellulitis (skin infection)
- When cutting your nails, take care not to damage the cuticles as it could cause cellulitis
- Avoid sunburn by using a high factor sun cream. Be aware that you can also burn through your compression garment if you are given one
- On your affected limb, try to avoid **repeated** needle-stick procedures such as blood tests, immunisations or tattoos, to reduce the risk of cellulitis. However, please do not worry in medical emergencies

Cellulitis/ Infection

The most common infection with lymphoedema is cellulitis. With cellulitis the area can be:

- red, or there can be a rash,
- hot to touch,
- tender or painful,
- your swelling may increase,
- you may feel generally unwell (as if you have the flu)

If you think you have cellulitis, 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 cellulitis from getting any worse. You will need antibiotics as soon as symptoms occur and you must take them for **no less than two weeks**. To further reduce your risk of cellulitis, take note of the following tips:

Risk	Reduce Risk
Cuts/scratches	Wear gloves when gardening
Burns	Use oven gloves
Hair removal	Use hair removal creams/electric shavers if possible
Insect bites	Use insect repellent/sprays if prone to bites
Fungal infections	Wash and dry your skin thoroughly and apply clean garments daily

Injuries

Treat all cuts, grazes, burns and bites as follows:

1. Clean the area well with water
2. Use an antiseptic solution or cream if possible
3. Cover with a sterile dressing or plaster
4. If in doubt seek medical advice
5. If the area becomes red, hot or painful, you may have cellulitis - seek medical help

2. Movement, Exercise, Activity

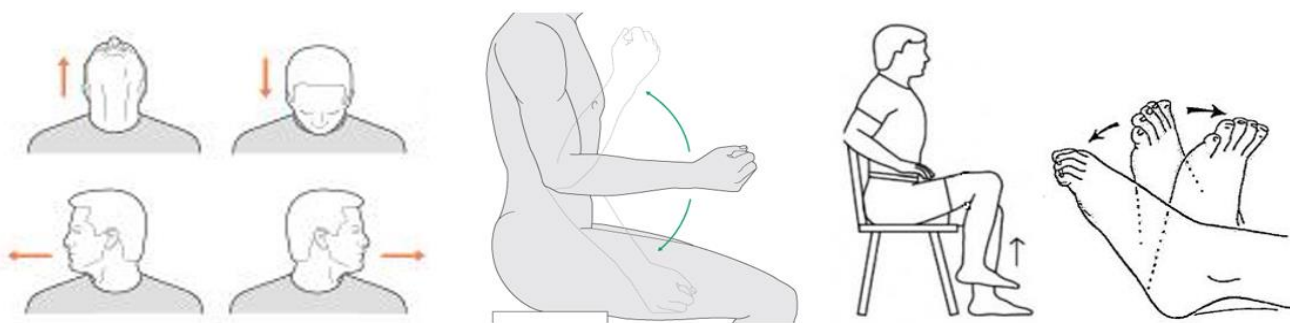
Movement, exercise and activity will help the muscles pump lymph fluid more effectively through your body. It helps you improve and maintain flexibility and keeps your bones strong. Being more active helps you achieve and maintain a healthy weight and may improve your emotional wellbeing. Activities such as walking

are ideal, as are swimming, cycling, bowling, gardening, housework and even shopping. Basically move your body. If you tend to sit a lot, then try getting up and moving around a little bit more every day.

If your mobility is limited, you can still move your body. Try lifting your arms and legs while sitting in the chair. Some people have found that dancing when music comes on or walking on the spot while waiting for the kettle to boil can help. Some watches and mobile phones can capture the numbers of steps you take every day. Keep a note of the amount you do. Ultimately the more you move your body, the more you move your lymph. Agree your activity programme with your therapist.

- We suggest that you wear your garment when exercising to improve the muscle pump action
- Try to do a little every day and build up to about 30 minutes of activity 5 days a week
- Pacing yourself is important. Use your common sense - listen to your body when it says I am tired
- Work jointly with your therapist to set personal and achievable goals
- Sometimes keeping a record of how much activity you do can be beneficial i.e. walked to the corner shop and back, walked upstairs 4 times

For more information on local walking groups and the National Exercise Referral Scheme ask your therapist or GP. Here are a few general exercises to get you started and your therapist will discuss some more exercises specific to you too.



3. Compression

There are different types of compression:

- Compression garments which are the main treatment in controlling and managing your lymphoedema
- Multi-layer Lymphoedema Bandaging is often used to reshape the swollen area, reduce the swelling and stop leaking fluid
- Compression wraps may also be used to reduce swelling in combination with compression garments

A compression garment lasts for 6 months of daily wear. You will receive two garments per limb to allow you to wear one whilst the other is being washed. Therefore, your compression garments should last for 9-12 months. Compression garments can be hand or machine washed but you should not use fabric conditioner as part of the wash cycle. All garments come with manufacturer's guidance and it is important you follow their instructions. Please do not keep one garment for best as this will not help to manage your swelling.

- Compression garments should be worn every day. You can start off using them for a few hours and the building up to all day. Your therapist will tell you how many hours but there are no rules. You are in charge of your lymphoedema and garments but the more you wear them, the more your swelling will reduce
- Compression garments need to be applied evenly over the limb so that there are no creases.
- Rubber or gardening gloves will help smooth out the garment preventing creases or folds as well as preventing ladders and pulls in the fabric
- Do not fold your garment over at the top as this will double the compression making it more difficult for the fluid to move off your limb. If you think your garment is too long for you, please talk to your therapist

- There are aids available to help get a garment on and off. Ask your therapist for advice
- Remember there are many different types of garments so if one is not suitable you can try another style.

If you develop increasing pain or discolouration when wearing your compression garment, remove it immediately and contact your therapist.

4. Weight Management

It is vitally important to maintain a healthy body weight i.e. a BMI (Body Mass Index) around 25. It is known that being overweight will make your lymphoedema worse as fat cells obstruct the flow of lymph. Therefore, if you put on weight, you risk making your swelling worse. Ask your therapist for support in managing your weight. Weight management is extremely important. Some patients who lose weight find that their lymphoedema greatly improves. Lymphoedema Wales Clinical Network has produced films that may help you. See the links at the end of this leaflet.

5. Lymphatic Drainage

There are two types of lymphatic drainage:

- Simple Lymphatic Drainage (SLD) is a lymphatic drainage massage which you are able to do for yourself. SLD aims to move the fluid from swollen areas. It is a very slow, gentle series of stroking techniques, exercises and breathing exercises. For best results, SLD needs to be done at least once a day and should take you between 15-20 minutes to complete. Your therapist will teach you SLD and provide you with a written information leaflet and link to a film.
- Manual Lymphatic Drainage (MLD) is a specialised Lymphatic Drainage massage for patients with severe or complex lymphoedema. Only qualified therapists can deliver this treatment in combination with skin care, exercise, SLD and compression.

General Recommendations

1. If you have swelling in the genitalia it is very important to wear undergarments. Underwear should be snug; so avoid wearing boxers and loose fitting knickers/pants
2. For patients with breast swelling it is essential that your bra is correctly fitted in the right style and size for your body shape. A full cup bra or sports bra is recommended.

Patient Story

John is 62 years old and a retired carpenter. He has suffered with swollen leaking legs for the last 5 years. He first noticed his ankles were swollen after having an episode of cellulitis. He had been diagnosed with a fungal infection in between his toes and had forgotten to apply the antifungal cream which was the reason for his repeated cellulitis. He found getting shoes to fit a massive problem affecting his mobility. His main hobby was watching the TV. His weight increased by 3 stone over the last few years. After being referred to the Lymphoedema Service John and his therapist worked on a joint treatment plan. The plan included: daily washing and drying of the skin; applying moisturising cream and using his antifungal cream. As John had experienced repeated cellulitis the therapist arranged with his GP for a prescription of long term prophylactic antibiotics to try and prevent further episodes. Two weeks of multi-layer bandaging stopped the leaking fluid and garments were provided. He was encouraged to start moving his legs whilst sitting in the chair and to walk a small distance daily. This extra activity and promotion of a healthy eating plan enabled John to lose a stone in weight over the next 3 months. Compression garments were worn daily from morning to evening. John can now wear his normal shoes and feels much better.

Follow the link or QR code to access all films about Lymphoedema.



Lymphoedema General

www.medic.video/w-lymph