

Lymphoedema Network Wales



General Information and Advice on Lymphoedema

Lymphoedema Network Wales was established in May 2011 and has dedicated lymphoedema clinics in all of the seven Health Boards in Wales. As a patient of this service you will be assessed, diagnosed and offered treatment based upon your clinical needs. This may include follow up appointments, intensive treatment and ongoing support to help you manage your condition. As lymphoedema can be lifelong, it is important that we work together to help you manage your swelling as independently as possible. Coproduction is embedded in Lymphoedema Network Wales principles. This means that you as a patient will work in partnership with your therapist to manage your lymphoedema successfully.

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 which cannot be drained by a needle. This fluid, known as lymph, is colourless, odourless but is rich in protein. High protein causes dryness of the skin, which can result in flaking, thickening and blistering. If left untreated, complications such as leaking fluid, ulcers, wounds and cellulitis (infection) can occur. It is not known how many people have lymphoedema but it is estimated in Wales that it affects at least 10,000 people. 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

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

Secondary lymphoedema is caused by damage to the lymphatic system. This can be following any surgery, radiotherapy, cancer, vein problems, trauma, some skin conditions including repeated cellulitis, immobility and obesity. In tropical regions it can be caused by a parasite called filiriasis; this is extremely rare in the UK.

It is possible to reduce lymphoedema developing further if the swelling is identified early and treatment is followed. For the majority of people with lymphoedema is a lifelong condition. Only a small proportion of people with mild lymphoedema may be suitable for super micro surgery which could improve the symptoms of lymphoedema.

Management of Lymphoedema

An assessment of your lymphoedema is vital. If you have been 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.

- Wash your skin daily with warm water and soap/soap substitute
- Dry your skin thoroughly especially between the fingers and toes
- Apply moisturising cream to your skin to prevent it from drying and cracking. Creams are considered better than lotions as the moisturising effect lasts longer
- Jointly, you and your therapist will decide which soaps and creams are suitable
- Daily skin care will help you to reduce your risk of infections, such as cellulitis
- When cutting your nails take care not to damage the cuticles
- Use your common sense in preventing sunburn by using a high factor sun cream. Be aware that you can also burn through your garment
- Avoid repeated needle-stick procedures such as blood tests, immunisations, acupuncture and tattoos if possible, on your affected limb to reduce the risk of an infection

2. Movement, Activity, Exercise

Gentle movement, exercise and activities 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 on the spot or walking your dog are ideal, as are swimming, cycling, bowling, gardening, housework and even shopping. Basically move your body!

If your mobility is limited, you can still move your body. Try lifting your arms and legs when in bed or on the chair. Some people have found that using a console (wii, x-box or similar) with games that allow you to play sports whilst sitting down can help. The more you move your body the more your 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.

3. Compression

There are different types of compression:-

- Compression garments are the main treatment in controlling and managing your lymphoedema
- Multi layer lymphoedema bandaging is often used to reshape, 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, compression garments should last you 9-12 months. Compression garments can be hand or machine washed but should not have 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 for best as this will not help to manage your swelling.

- Compression garments must be worn daily from morning until evening, or as agreed jointly with your therapist
- Compression garments need to be applied evenly over the limb.
- Rubber gloves will help smooth out the garment preventing creases or folds as well as preventing ladders and pulls in the fabric
- There are aids available to help get a garment on and off. Ask your therapist for advice.

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 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. Lymphoedema Network Wales have produced a Video Prescription that you can receive in supporting healthy eating.

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 will move fluid from the swollen areas. It is a very slow, gentle series of stroking techniques 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
- 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. It is important to wear your compression garment when doing repetitive activities such as ironing, typing, and vacuuming.
2. If you have swelling in the genitalia area it is very important to wear undergarments. Underwear should be snug; so avoid boxers and loose fitting knickers/pants.
3. 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/sports bra is recommended.

Cellulitis/ Infection

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

- red or 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 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 you must take them for **no less than two weeks**.

To further reduce your risks to infection, take note of the following:

Risk	Reduce Risk
Cuts/scratches	<ul style="list-style-type: none"> • Wear gloves when gardening • Use a thimble when sewing • Wear suitable and correctly fitted shoes and slippers
Burns	Wear oven gloves
Hair removal	Use hair removal creams/electric shavers (avoid razors or waxing if possible)
Insect bites	Use insect repellent/sprays
Fungal infections	Wash and dry your skin thoroughly and apply clean garments daily

Injuries

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
4. If in doubt seek medical advice
5. If the area becomes red, hot or painful, you may have an infection - seek medical help.

Patient Story

John has suffered with swollen leaking legs for the last 5 years. He first noticed his ankles were swollen after having a cellulitis infection. 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 and therefore his mobility and social life had reduced. He spent most of his time sitting in the chair watching the TV and his weight has increased by 3 stone over the last few years. After being referred to the lymphoedema clinic John and his therapist worked on a joint treatment plan that would support him in being able to go and watch his local rugby team. A plan included:- daily washing and drying of the skin with cream applied as well as his antifungal cream. As John had experienced repeated cellulitis the therapist arranged with his GP long term prophylactic antibiotics. The therapist arranged two weeks of multi layer bandaging to stop the leaking and prescribed temporary bandaging shoes. He was encouraged to start moving his legs whilst sitting in the chair and to start a daily walking plan. This extra activity and promotion of a healthy eating plan enabled John to lose a stone in weight over the next 3 months. The leaking legs stopped after bandaging and he was able to recommence wearing his own shoes. To maintain this improvement compression garments were prescribed and worn daily.