

# **Scottish Muscle Network**

Patient information leaflet

## **Managing Oedema and circulatory problems in neuromuscular disorders**

## Introduction

Oedema, sometimes known as Lymphoedema or fluid retention, is the build-up of fluid and other elements (such as protein) in the tissues. This fluid retention often causes swelling in the feet and lower legs as well as other areas of the body. Some people with a neuromuscular disorder are prone to oedema as they are sitting for long periods of time.

Gravity encourages blood flow into the legs and because the muscles in the legs and feet are weak, shifting this fluid back up into the body becomes more difficult as the circulation is working against gravity.

## What is Oedema?

The lymphatic system is a complex system of fluid drainage and transport and is part of our immune response and disease resistance system. Fluid is moved out of the bloodstream during normal circulation and is filtered through lymph nodes to remove bacteria, abnormal cells, and other matter. This fluid is then transported back into the bloodstream via the lymph vessels. Lymph fluid only moves in one direction, toward the heart.

When oedema starts to develop in the legs, this is caused by an imbalance between the amount of fluid produced in the tissues (interstitial fluid) and its transport system. If the oedema has been present for a while, chronic lymphoedema may occur and this is when fat deposits collect in the tissue making it more difficult to move the oedema. Managing chronic oedema is more challenging and the feet and legs may not be able to return to their original size.

In some cases, the cause of the oedema may be due to an underlying heart problem, and this should be monitored via the cardiology service. If you do have a heart condition, you should discuss any new treatment for the oedema with your heart nurse or doctor.

## Symptoms of Oedema

When the foot and lower leg swell, the increase in size can make it more difficult to find suitable footwear, socks, and clothing. Moving and handling can be more challenging, and people often report a feeling of discomfort when their legs are swollen. The swollen tight skin can also increase the risk of cellulitis, or another similar skin condition called erysipelas. Sometimes you may need antibiotics.

## Management of Oedema

There are several ways that you can help to reduce the swelling in your legs and usually a combination of these different methods is most successful. You will need to keep going with the treatment as oedema can be persistent and people who are prone to swelling usually find that as the day progresses, they have some swelling in their legs and ankles.

Tight clothing and especially tight clothing around the feet and ankles can make the oedema worse as anything that restricts the circulation will slow the lymphatic drainage. Static postures and lack of movement can increase the swelling, particularly if you use a wheelchair and your legs are “dangling”. Therefore, good foot supports at the correct angle and height are necessary. Being overweight can increase the chance of oedema and a balanced diet is therefore essential. Some people also find if they are going abroad, long flights can increase the swelling, as well as the heat when they get to their holiday destination.

## How can I help my Oedema?

There are several ways you can help manage your oedema that you can do by yourself or with the help of a carer.



**Elevation**: Sitting with your feet up regularly through the day helps to “drain the fluid” from the legs as gravity will help move the fluid back into circulation. Ideally, you should place your feet higher than your hips although any elevation is better than none. Your legs should be supported the whole way down, so you are spreading the weight of them, which is more comfortable and prevents the build-up of pressure in certain areas like the heels or calves.



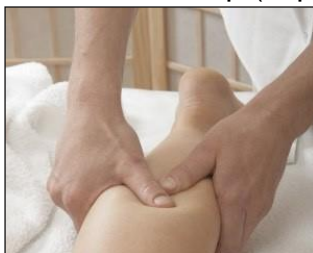
It also protects the knee joint if your leg is fully supported. When your muscles are weaker, your joints rely on the musculature around them for support so protecting the knee joint with a pillow or stool reduces the work of the muscle allowing the circulation to flow more freely.

If you are sitting for long periods of time, it is generally recommended that you have your feet raised for 20 minutes every hour. Some people alternate having their feet up when sitting and feet up when lying down.

Whilst you can position your legs comfortably with pillows, there are various contoured positioning pillows available to buy that some people prefer. If you are tired through the day, it is a good idea to get into bed for a nap rather than sit and snooze in your chair. This way you are in a fully stretched out position and the lymphatic flow (flow of fluid) will work more effectively whilst you sleep or rest.

### **Massage:**

**Traditional massage techniques:** Massage will not only help get static fluid moving but will also help improve the subcutaneous (under the skin) tissue consistency through the different techniques combining compression, movement, and relaxation. Your physiotherapist can show you ways to massage your legs or have a partner or carer massage your legs for you. By applying a mixture of circular movements, long deep strokes (effleurage), and kneading movements (petrissage) applying pressure in an upward motion towards the body, you can help move excess fluid by moving the tissues, kneading the muscle, and influencing the circulation in a positive way. You can sit or lie down during massage however, to maximise the benefits of massage it is best to lie down in the most comfortable position which may be either face up (supine) or face down (prone).



**Hydrotherm Massage:** Some people prefer to have massage within their wheelchair and another good form of massage is hydrotherm massage. This is a deep, comfortable form of massage and will have more benefit in terms of relaxation. This involves being moved or hoisted out of your chair and two large cushions filled with warm water are put into the chair and then you sit on top of them. The warm water helps the muscles relax and you will feel supported and experience the sensation of floating. The therapist slides their hands between your body and the cushion and works against your body weight in upward strokes. Some therapists can do this form of massage in your own home. For more information, please visit the link below:

<https://www.fht.org.uk/therapies/hydrotherm-massage>

**Compression Techniques:** Compression garments are a good way of maintaining pressure around the legs and feet. The key to managing your oedema with these garments is to have a specialist Lymphoedema nurse, Tissue viability nurse, District or Practice Nurse who will measure your legs accurately. The pressure garments come in different strengths of compression and the precise prescription will depend on the severity of the oedema, whether “pitting” is present (indentation marks upon pressure of the limb) and your ability to tolerate the degree of compression. Compression garments usually last between three and six months. Caring for your garments is important to maintain the elasticity. You should discuss:

- how long you should wear the garment each day
- the best way to put the garment on and take it off.

Even if the swelling is below the knee, a full-length stocking is recommended to help move the swelling the whole way up the leg rather than stopping at the knee where it can become static. Some people may need help with this and often these stockings are best put on before getting out of bed, as there is less swelling in the morning.

**Intermittent Pneumatic Compression (Flowtron Therapy):** Intermittent Pneumatic Compression (IPC) consists of an electric air compression pump attached to an inflatable garment. The garment inflates and deflates for a set period which can vary from thirty minutes to two hours. The pressure produced can be varied according to the level of swelling and your own comfort. These garments can be single chambered or multi chambered that are sequentially inflated to provide a progressive wave like movement (peristalsis) to improve the circulatory flow.



**Stretching and Movement:** Your physiotherapist can show you specific stretches to help the feet, ankles, and lower legs. These stretches combined with active movement, active–assisted movement or passive movement (please refer to “[An active lifestyle: What is suitable activity for people living with a muscle disorder?](#)” leaflet that can help manage symptoms of oedema.

Regular movement and stretching improves the effectiveness and efficiency of the muscle. When muscles contract and relax, the blood flow through that area automatically improves because of the changes in pressure within not only the muscle but the surrounding tissues. If the activity you are participating in gets you

breathing a bit more deeply and a little faster, this increases the pressure within the abdomen (intraabdominal pressure) and can also assist the blood and lymphatic drainage flow around the body.

**Skin Condition:** If oedema is present, good skin care is vital to prevent skin conditions such as cellulitis developing. If skin becomes dry and cracked, the healing process of open sores can take longer so keeping the skin well moisturised is important. Making sure you are well hydrated throughout the day with water for example, (rather than coffee or tea or drinks containing caffeine) and getting plenty of fruit and vegetables into your diet will also be helpful when looking after your skin.

**Circulation:** Whether oedema is present or not, circulation in neuromuscular conditions can be problematic, particularly if you are in a wheelchair. Feet and hands can vary in colour from being white, pink or red to blue. The poor circulation can affect the skin condition and all the measures already discussed in this leaflet are helpful. Using a combination of these measures everyday should become part of your daily routine.

When managing circulatory difficulties, the first rule is not to let the limb get cold. The use of thermal base layers and layering socks and gloves is helpful. Some people find silver nitrate gloves or heated gloves and socks useful, and you can buy these from outdoor shops. If limbs do get cold, it is best to heat them up gradually. Heat devices such as heat pads, wheat bags, hot water bottles etc can all be useful, but it is important to remember that heat will increase the blood flow to that area and improving circulation is about increasing the blood flow to the limb as well as improving the blood flow away from the limb.

Always take care when using heated products (e.g. heat pads) as it is important to avoid a burn or scald. To improve the blood flow away from the limb, all the techniques above including, elevation, massage, stretches and activity and compression are useful.

## **Conclusion**

Managing oedema and poor circulation is about using a combination of all the above approaches daily. Using these different techniques every day can help prevent chronic oedema developing and can help reduce swelling that has become more persistent. For further information on your oedema or circulation concerns, please contact your family doctor, physiotherapist, or practice nurse.