



Advice for patients at risk of developing lymphoedema



Conditions related to increased risk of developing lymphoedema:

High risk referral criteria <i>Do you have any of the following?</i>	Additional criteria for increased risk <i>Do you have 2 or more of the following?</i>
Recurrent skin infections (cellulitis)	Obesity
Family history of lymphoedema (mostly limb swelling) - genetic/ inherited lymphatic anomalies	Recurrent ulceration e.g. leg ulcers (damaged lymphatic circulation as a result of vascular disease)
Surgical removal of lymph glands (nodes) or radiotherapy treatment to this area e.g. armpit, groin or neck	Reduced mobility
	DVTs (deep venous thrombosis)
	Coronary artery by-pass graft
	Chronic wounds

This booklet contains important information about lymphoedema. If you have any of the high risk criteria from the table opposite, and/or two or more of the additional criteria, you may be at risk of developing lymphoedema and the following advice will help you:

- to understand the condition
- to reduce your risk of developing lymphoedema
- to recognise the early signs of lymphoedema

More information about lymphoedema, including details of your local lymphoedema service and how to access it, can be found online via the Lymphoedema Network Northern Ireland website at www.lnni.org.

What is lymphoedema?

The lymphatic system is a network of vessels that carry a fluid known as lymph (containing water, electrolytes, proteins and other substances) from the body's tissues. Lymphoedema is the swelling that occurs as a result of a blocked or damaged lymphatic system.

Lymphoedema usually develops in the legs or arms (refer to pages 4 and 5), but can occasionally also develop in the head and neck area, breast and trunk, and genital regions. Some people may have only swelling in one leg or arm, but others may develop swelling in several different parts of the body.

This swelling will cause physical changes, but may also cause psychological stress due to the change in shape, problems with fitting clothes or shoes, and potential reduced mobility. If you feel that you may need access to counselling, please discuss this with your Health Care Professional.

There are two types of lymphoedema:

1. Primary lymphoedema

This is usually determined from birth due to the underdevelopment of the lymphatic system or absence of lymphatic tissues. It can be present at birth or develop at any stage in life but particularly in adolescents or in mid-thirties. It is a life-long condition that, with help, can be controlled.

2. Secondary lymphoedema

Secondary lymphoedema is caused by trauma or damage to the lymphatic system. This life long risk of developing lymphoedema could be as a result of surgery or radiotherapy to treat cancer. It can also occur as a result of infection, severe injury, burns or any other trauma which may affect the lymphatic system. Examples include:

- Skin infections (cellulitis)
- DVT
- Chronic vascular condition such as leg ulcers or chronic wounds
- Obesity and reduced mobility will also have an impact.

Lymphoedema is a chronic condition and will need to be managed throughout life. With proper education and care, the swelling can be reduced and controlled.



Advice for patients 'at risk' of developing lymphoedema

While there is no strong scientific research into how lymphoedema starts, it is believed that you can reduce the risk of lymphoedema by incorporating simple precautionary measures into your lifestyle – looking after your skin, a healthy diet and following a simple exercise programme can help.

How does lymphoedema affect the body? - What are the signs / symptoms to look out for?

Early signs of lymphoedema may be slight and not noticeable all the time. The swelling may not be as much in the morning, but may become larger in the affected area or limb as the day goes on. If left untreated the swelling may become more permanent and may not go down overnight. The swollen area may begin to feel hard and solid. The skin can also become thickened or gain an orange peel appearance. This is because protein, as well as fluid, has built up in the tissues. Patients may experience symptoms of heaviness, aching or stiffness in the affected area or limb. These symptoms may be felt before the swelling is obvious. It may also be difficult to get clothes, shoes and jewellery to fit.

It is important to start treatment as soon as possible as simple measures may help to reduce swelling in the early stages.



What should you do to reduce the risk of developing lymphoedema?

1. General Recommendations:

- It is very important to keep your weight within normal limits as excess weight can increase strain on the lymphatic system. Following a normal, healthy diet is recommended; reducing protein in the diet will not prevent lymphoedema.
- A Body Mass Index (BMI) of greater than 25kg/m² will increase the risk of developing lymphoedema.
- Avoid prolonged periods of standing in one position
- Short periods of daily leg elevation (on a sofa or bed) are recommended. It is not good to always be standing or sitting with the legs down i.e. in a chair

2. Skin care

Skin care is essential in the prevention and management of lymphoedema in order to maintain good skin quality and reduce the risk of infection. Part of the lymphatic system is a fine network of vessels running just below the skin. These vessels help to remove any extra fluid and waste substances from the body's tissues. It is therefore essential to look after the skin to prevent it becoming dry, cracked or broken.

Damaged skin can lead to an infection called **cellulitis** which can increase the risk of developing lymphoedema. Contact your doctor immediately if you notice that your skin has become red, hot and tender, as you may have an infection. This may be preceded by flu-like symptoms.

Cellulitis must be treated quickly with antibiotics prescribed by your doctor.

In order to try to prevent infections, and thereby lymphoedema, it is important to look after your skin:

- Cleanse your skin daily using unscented soap and then moisturise using a cream/lotion and gentle strokes
- Take care when removing hair - electric razor can be less traumatic
- Seek medical advice if a sore/wound does not seem to be healing
- Take care to avoid injury
- There is currently no evidence that manual lymphatic drainage adds any benefit in lessening the chance of developing lymphoedema in those 'at risk' (Stuiver et al 2015)

For those at risk of upper limb (arm) lymphoedema:

- Use gloves, e.g. when gardening or using a hot oven, to decrease risk of trauma and cellulitis
- If possible, use contralateral (other) limb for venepuncture/blood pressure

monitoring (does not apply in emergencies).

For those at risk of lower limb (leg) lymphoedema:

- Avoid walking barefoot or wearing shoes that may cause blisters
- Treat any fungal infection (Athletes Foot) as soon as possible.

- 3. Gentle rhythmic exercises** will help to pump the muscles and remove the build up of lymph in the body. It is important to keep as active as possible; swimming, walking and cycling are excellent ways to use large muscles and help to prevent lymphoedema.

All exercise should start slowly, *and be progressed gradually*, including resistance training.

Exercise is also important for healthy weight management which will also help to reduce the risk of lymphoedema.

4. Holidays and travel:

- Flight socks should fit correctly, be comfortable and not leave pressure marks on your legs. Poorly fitted flight socks could cause more problems.
- Stretch and move around as much as possible when travelling
- Skincare is very important on holidays; avoid sunburn and insect bites by using sun cream/insect repellent and avoiding excessive sun at the hottest times of the day
- Prevent dehydration by frequently drinking water.

5. Complementary and alternative therapies

- Check that your therapist is a current member of a recognised professional body for their form of therapy.

What should you do if you notice swelling?

If you notice swelling, and even if it comes and goes, you should tell your GP or current health care provider and ask to be referred to a trained lymphoedema therapist.

Early treatment is always recommended when the swelling is soft and easily managed.

What treatment can I get if I begin to develop lymphoedema?

Your doctor will refer you to a trained lymphoedema specialist for assessment and treatment.

The therapist will suggest a number of treatment options which may include complex decongestive therapy (CDT). CDT consists of gentle massage (manual lymphatic drainage - MLD), multi-layer bandaging, skin care and exercises.

Lymphoedema is a long-term condition which means that you will need to learn new skills to help support the work of the therapist, and to learn what you can do to improve your own condition. The therapist will work with you to develop these skills.

The treatment aims to restore limb size and function and reduce swelling caused by the build up of lymph.

More information about lymphoedema can be found online at www.Inni.org

Useful contacts

Lymphoedema Network Northern Ireland (LNNI)

Email: info@lnni.org
Web: www.lnni.org
Tel: 028 9504 8545

Lymphoedema Support Northern Ireland

PO Box 851
BT9 6WY

Tel.: 028 9066 7570
Email: info@lymphoedemasupportni.org
Web: www.lymphoedemani.com

The Lymphoedema Support Network (LSN)

St Luke's Crypt
Sydney Street
London
SW3 6NH

Tel.: 020 7351 4480
Email: admin@lsn.org.uk
Web: www.lymphoedema.org

The Citizens Advice Bureau

can provide an on-line advice guide to provide information on financial support if required (www.adviceguide.org.uk/nireland.htm).

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References:

1. NICE (2018) CG81
2. British Lymphology Society (2019)-Lymph Facts.

