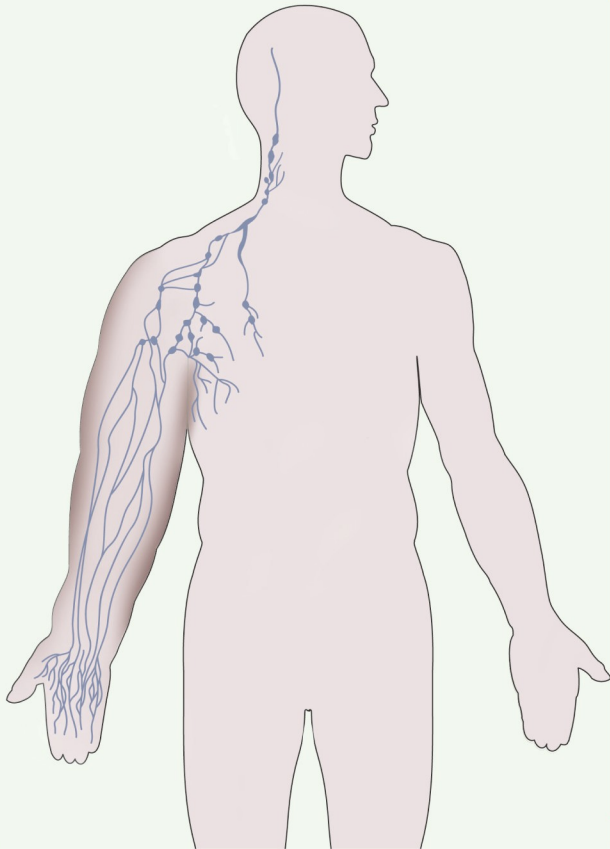
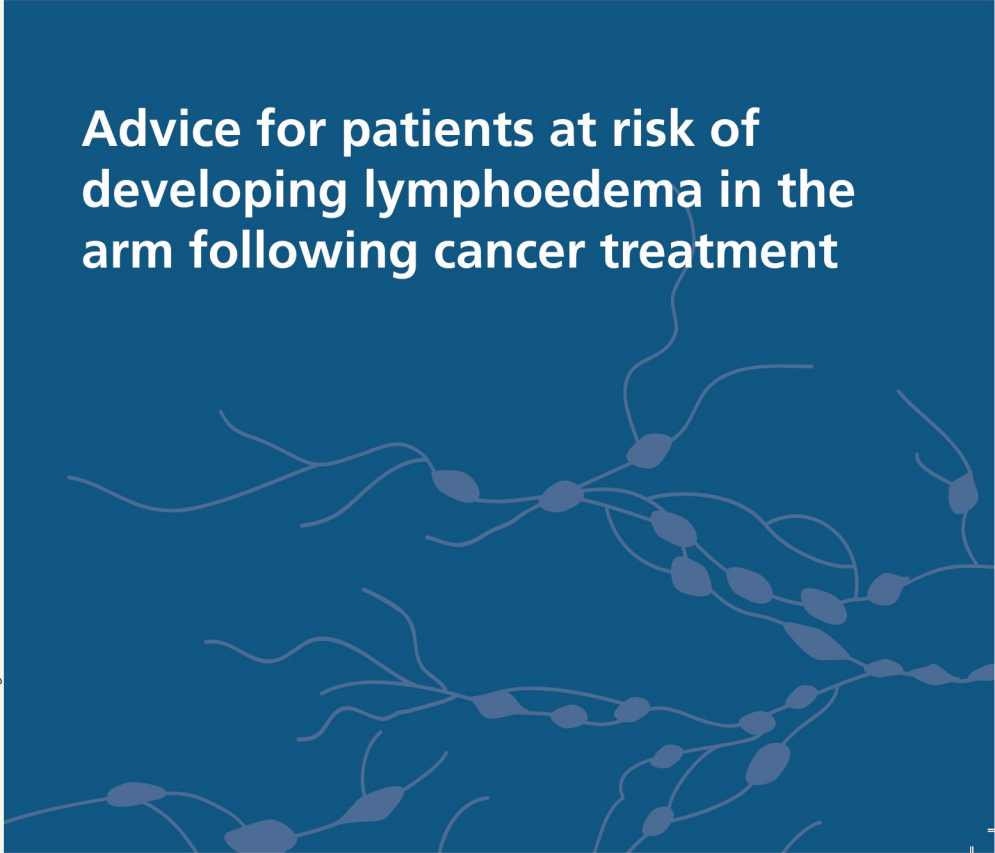




Health and  
Social Care



## Advice for patients at risk of developing lymphoedema in the arm following cancer treatment



## **This booklet contains important information about lymphoedema**

You are at risk of developing lymphoedema if you have had surgery or radiotherapy to your breast and the surrounding area, including the armpit. The level of risk does depend upon the type of surgery and other cancer treatments. Research also suggests that the following will also increase the risk:

- Being overweight
- Skin infections (also known as cellulitis)
- Reduced mobility of the shoulder

The following advice will help you:

- to understand the condition
- to try to reduce your risk of developing lymphoedema
- to recognise the early signs of lymphoedema, and know how to seek an early referral to your local lymphoedema service.

More information is available on the Lymphoedema Network Northern Ireland website ([www.lnni.org](http://www.lnni.org)), including how to access local lymphoedema services.

## **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 when the lymphatic system becomes blocked or damaged, for example, when lymph nodes are removed. Lymphoedema usually develops in the arm or hand, but can occasionally develop in the breast and trunk.

Lymphoedema can occur within a few months, a couple of years, or 20 years or more after cancer therapy. It most frequently occurs in the first 2 to 3 years post-surgery.

## **How does lymphoedema affect the body?**

Early signs of lymphoedema may be slight and not noticeable all the time. Initially this can just feel like tightness in the arm.

There may be little or no swelling in the morning, but the swelling may increase in the affected area as the day goes on. If left untreated the swelling may become more permanent, and may not go down overnight. The swollen area can 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.

Swelling may appear in the arm, hand, fingers or breast, similar to the photographs shown below:



People may experience symptoms of heaviness, aching or stiffness in the affected area or limb. This may make it a bit more difficult to carry out simple everyday tasks. Symptoms sometimes can be felt before the swelling is obvious. It can be difficult to get clothes and jewellery to fit.

### **Advice for patients 'at risk' of developing lymphoedema**

It may be possible to reduce the risk of developing lymphoedema by incorporating simple measures into your lifestyle – looking after your skin, keeping to a healthy diet and following a simple exercise programme will help.

Once lymphoedema develops it cannot be cured, but it can be improved and controlled by following a straightforward treatment programme. This aims to restore limb size and function, and decrease heaviness.

## 1. General Recommendations to reduce the risk of developing lymphoedema:

- It is very important to keep your weight within normal limits, as excess weight will increase strain on the lymphatic system and increase the risk of developing lymphoedema.

Following a normal, healthy diet is very important. (Reducing protein in the diet will not prevent lymphoedema)

Body Mass Index (BMI) is a term used to describe state of health related to weight and height. The risk of developing lymphoedema will increase if the BMI is greater than 25kg / M<sup>2</sup> (i.e. the overweight /obese ranges). Many BMI calculators are available free online, or your GP or healthcare professional can calculate this measurement for you.

- Avoid prolonged periods of standing in one position with the arms hanging down, or long periods of carrying heavy bags.
- It is recommended to elevate your arm for short periods daily e.g. along the back or side of a sofa or chair.
- Ensure that all underwear is well fitting, supportive and comfortable. A bra should give good support from the side too. Underwear should not leave red marks on the skin; if this happens, it is too tight.

## 2. Skin care

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. Skin care is very important in decreasing the risk of lymphoedema. This is important around the nail area too.

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 and require antibiotics. This may be preceded by flu-like symptoms.

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



## Look after your skin:

- Every day wash your limb in warm water and dry it well. Then moisturise your skin using gentle strokes. Soap and creams/moisturisers should be unscented.
- Take care when removing unwanted hair from the 'at risk' part of the body e.g. armpit. An electric razor may be less traumatic.
- Use nail clippers or emery boards rather than nail scissors.
- Try to avoid injury to the limb e.g. use protective gloves when gardening or reaching into a hot oven to decrease the risk of injury.
- Monitor the affected limb for any cuts or areas of dry skin. Use an antiseptic when necessary, and seek medical help if a sore or wound does not seem to be healing.
- If possible, use the contralateral (other) limb for venepuncture / blood pressure monitoring. There may be instances when the medical or nursing staff may need to use either limb.
- There is no evidence that manual lymphatic drainage (MLD) adds any benefit in lessening the chance of developing lymphoedema for those who are 'at risk' (Stuiver et al 2015).

### 3. Be active!

Rhythmic exercises will help to pump the muscles, which helps to remove the build-up of lymph in the arm.

For example, to start, gentle repetitions of the following exercises will be beneficial:

- Slow 'boxing', 'rowing' or 'breast stroke' type movements
- Slow bending/straightening of elbow and wrist
- Make a fist and then straighten your fingers

The intensity of the exercises can be slowly progressed to be more vigorous.

Swimming, or any activity in water, is an excellent form of exercise for those at risk of developing lymphoedema in the arm.

Exercise is also an important part of maintaining a healthy weight, which, as already mentioned, will reduce the risk of developing lymphoedema.

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

#### **Other benefits of activity include:**

- Reduces **tiredness** and increases **energy** levels
- Increases **strength** and **flexibility**
- Keeps **bones** strong, reducing the risk of osteoporosis
- Improves **mobility** - allowing you to do the things you enjoy
- Decreases **nausea**



- Improves **circulation**, reducing the risk of blood clots
- Improves your **immune** system
- Reduces **anxiety** and **depression**
- Helps to reduce the risk of some breast cancers recurring

Activity can come in many forms, such as walking, cycling, gardening, dancing or an organised sport, but most importantly find something that you enjoy! It is worth noting the National Institute of Clinical Excellence (NICE) recommendations for all adults and their weekly activity goals:

- **Fitness:**

- 150mins of moderate intensity exercise per week (or 30mins most days that can be carried out in smaller bouts of 10mins or more)

- Do this at a moderate intensity level – that is, an activity that causes you to become moderately breathless, but still allows you to have a conversation

- Or**

- 75mins of vigorous intensity exercise spread out over the course of the week

- Or**

- a combination of both vigorous and moderate activity

- **Strength**

Twice a week, adults should aim to carry out strength activities e.g. exercising with weights, yoga or Pilates.

- **Balance** (if you're over 65 and at a risk of falling)

Activities such as Tai Chi and Yoga help improve flexibility, balance and co-ordination.

#### **4. Posture and Healing**

Immediately after surgery, the chest area may feel painful, tight or tender. Initially it may feel more comfortable to try to protect the chest area, and to take up a forward, hunched position. Overtime this hunched posture may cause the shoulder and chest muscles to tighten and weaken, and this can lead to further pain along the shoulders, neck and back. A few days after surgery, it is therefore very important to think about improving the posture again.

**Good posture is very important to prevent shoulder, neck and back pain, and to help scar healing. Abnormal posture and tight scars can reduce the effectiveness of the lymphatics too.**

## Good posture means:

- Keep the chin tucked in
- Keep the shoulders relaxed and down
- Keep the head in the middle, above your shoulders
- Draw the shoulder blades backwards

Normal scar tissue develops at the site of surgery because of the natural healing process. Sometimes the tissue at the scar can become thickened and tight. You may feel a tightness across the chest as you try to move your arm, but it is important to gradually stretch and move the scars to help healing and aid lymphatic flow.

Sometimes a 'cord' or tight band can develop that runs along the arm, and sometimes into the wrist or chest wall. This is usually noted when trying to reach or stretch up.

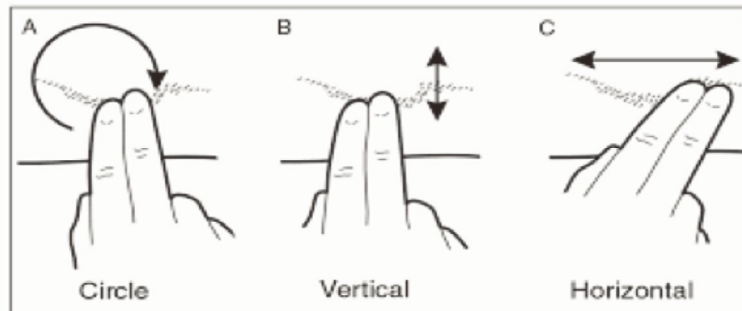
If this appears, massage daily along the length of the tightness but not over any broken or red skin. Also continue with the daily exercises and stretches.

It is good to start gentle scar massage once the scar has healed (talk to your surgeon at your post-op review (approximately 4-6 weeks after the operation)). If having radiotherapy, avoid massage during that period, however keep the breast and arm area well moisturised throughout. The Radiographer will provide advice regarding moisturising creams. Massage can restart after any pinkness from the radiotherapy has gone.

### Scar massage:

- With the tips of 2 or more fingers, gently apply pressure to the scar and surrounding area
- Move fingers in 3 different directions as shown in the picture below
- It can be easier to start by working around the scar first (above and below it), then move slowly across the whole length of the scar and surrounding tissues
- Only apply as much pressure as is comfortable; press down until scar lightens and turns white
- You can use lotions / cream to moisten scar

If you require more advice on scar massage or treatment for cording, please contact your Physiotherapist or Breast Care Nurse.



## 5. Holidays and travel:

- Stretch and move around as much as possible when travelling.
- There is no evidence to suggest that wearing a compression garment when flying reduces the risk of developing lymphoedema, and an inappropriate or ill-fitting garment may cause other problems.
- Skincare is very important on holidays:
  - Avoid sunburn by using sun cream/covering up, and avoiding excessive sun at the hottest time of the day.
  - Insect repellent and covering up will also help to prevent insect bites.
- Keep hydrated by frequently drinking water.

## 6. Complementary and alternative therapies

Check that your therapist is a current member of a recognised professional body for their form of therapy. Complementary therapy should be completed by a trained professional.

### What should you do if you notice swelling?

If you notice swelling anywhere on your arm, hand or breast/trunk area (even if it comes and goes), tell your GP or current health care provider, and ask to be referred to a trained lymphoedema therapist. Referral details are on the LNNI website, and the GP can refer electronically.

**A prompt referral to the lymphoedema service is advised.**

**Early treatment is always recommended. At this initial stage, the swelling is soft and easily managed which, can produce better treatment results.**

## **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 manual lymphatic drainage (MLD), multi-layer bandaging, skin care and exercises. The treatment aims to restore limb size and function, by reducing the swelling caused by the build-up of lymph.

Lymphoedema is a long-term condition, which means that you will need to learn to care for your limb. The therapist will teach you skills to help improve and manage your condition. Supporting information and videos are available on the LNNI website.

**The swelling can be reduced with proper education and care.**

**A self-management programme is important to help control the swelling.**

**Life-long lymphoedema management is required.**



Treatment for breast cancer can cause a change in body appearance and, swelling associated with lymphoedema may alter this again causing problems psychologically and physically, such as difficulty getting clothes to fit well. If you develop lymphoedema and feel you may need support such as counselling, please discuss this with your Health Care Professional.

**More information about lymphoedema can be found online: [www.lnni.org](http://www.lnni.org)**

## Useful contacts

### *Lymphoedema Network Northern Ireland (LNNI)*

Tel: **07710 145368**

Email: [info@lnni.org](mailto:info@lnni.org)

Web: [www.lnni.org](http://www.lnni.org)

### *The Lymphoedema Support Network (LSN)*

St Luke's Crypt  
Sydney Street  
London  
SW3 6NH

Tel.: **020 7351 0990**

Email: [admin@lsn.org.uk](mailto:admin@lsn.org.uk)

Web: [www.lymphoedema.org](http://www.lymphoedema.org)

### *Lymphoedema Support Northern Ireland (LSNI)*

PO Box 851  
BT9 6WY

Tel.: **028 9066 7570**

Email: [info@nilsg.co.uk](mailto:info@nilsg.co.uk)

Web: [www.nilsg.co.uk](http://www.nilsg.co.uk)

### *The Macmillan Support and Information Centre*

77 – 81 Lisburn Road, Belfast, BT9 7AB

**028 9063 8980**

Email: [cancer.info@belfasttrust.hscni.net](mailto:cancer.info@belfasttrust.hscni.net)  
(beside the Belfast City Hospital)

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](http://www.adviceguide.org.uk/nireland.htm)).

### *Cancer Focus NI*

[www.cancerfocusni.org](http://www.cancerfocusni.org)

Tel: **028 9066 3281**

## *Action Cancer*

[www.actioncancer.org](http://www.actioncancer.org)

Tel: **028 9080 3344**

**This website can direct you to services in your own area:** [www.survivorship.hscni.net](http://www.survivorship.hscni.net)

Physical activity support for patients after a breast cancer diagnosis:

- **Macmillan Move More NI**  
[www.facebook.com/movemoreni/](https://www.facebook.com/movemoreni/) **07587 657488**
- **Lagan Dragons**  
[www.lagandragons.com](http://www.lagandragons.com) **07708 274319**

The following website offers a wide range free downloadable audio files and booklets with specific information about fatigue, finances, physical activity plus many more.

Be Macmillan: [www.be.macmillan.org.uk](http://www.be.macmillan.org.uk)

## **References:**

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

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