Reducing the risk of developing lymphoedema

You have been given this leaflet as you are considering surgery to remove one or more lymph nodes. It is important that you know how to reduce the risk of developing lymphoedema and to recognise its symptoms. It is also important to remember that not everyone undergoing surgery will develop lymphoedema; the risk is estimated to be approximately:

- 2% (one in 50) for patients having sentinel lymph node biopsy (SLNB), and
- 30% (three in 10) for patients having completion lymph node dissection (CLND).

What is lymphoedema?

Lymphoedema is a chronic swelling which can affect any part of the body but is most commonly seen in an arm or leg. In order to understand how lymphoedema occurs, it is important to have an understanding of the lymphatic system in general – what it is and how it works.

The lymphatic system:

The lymphatic system forms part of your immune system, helping to deal with infection at a local level but just as importantly it is responsible for cleansing your tissues and maintaining a balance of fluids in your body. It can be likened to a waste disposal system, taking fluid, bacteria, proteins and waste products away from the tissues around skin, fat, muscle and bone.

Once inside the lymphatic vessels the fluid becomes known as 'lymph' and it is then transported in one direction by increasingly larger and deeper lymphatic vessels. Lymph is helped on this journey by squeezing of these vessels as a consequence of muscle movement (exercise), the contraction of the vessels themselves and gravity.

At some point in its journey, lymph will pass through a lymph node (sometimes called a gland). Clusters of these nodes are found in the neck, armpits and groin. It is here that the lymph is filtered and cleansed, so that the waste matter and harmful cells can be identified and removed by the body's defence system.

Having passed through these nodes, lymph finally drains back into the large veins of the body at a point just behind the collarbone, on each side of the neck. From here it goes back to the heart and is eventually removed from the body as urine through the kidneys.
How does lymphoedema occur?

If, for whatever reason, the drainage routes through the lymphatic system become blocked or damaged, lymph accumulates in the tissues and swelling (oedema) occurs. Lymphoedema can be described by medical professionals as primary or secondary.

**Primary lymphoedema** is generally thought to be the result of a genetic abnormality of the lymphatic system determined before birth.

**Secondary lymphoedema** is the result of damage to the lymphatic system that prevents it working properly. Examples of secondary lymphoedema are:

- Surgery – particularly when lymph nodes are removed as either a test or treatment for cancer: for example SLNB or CLND for melanoma.
- Radiotherapy – this is used to kill cancer/tumour cells, but it can also cause scar tissue that interrupts the normal flow of lymph in the lymphatic system.
- Accidental trauma/injury or infection that may damage the lymph vessels and therefore reduces drainage of lymph.
- Reduced mobility/paralysis – muscle contractions (during activity/exercise) are important to help the lymph to move.
- Problems with veins not working very well (varicose veins/after deep vein thrombosis) – often known as venous insufficiency. This results in the lymph system becoming overloaded and unable to function effectively.
- Cancer itself may also result in a blockage of the lymphatic system.

Recognising lymphoedema

Symptoms of lymphoedema can develop immediately after the causative event, or it can appear, without warning, months or years later and include the following:

- Swelling of the affected limb(s). This may initially be intermittent and may well reduce overnight. Depending on which limb is affected shoes or jewellery may feel too tight and clothing may feel too small.
- Tightness or tension in the limb(s) as the surrounding skin is stretched.
- As the limb(s) increase in size, there is often a feeling of heaviness.
- The swelling may *pit* in the form of a temporary indentation that appears when pressure is placed on the swollen area.
- Discomfort in the affected area as the swelling interferes with nerve endings.

Lymphoedema usually develops gradually and it does not always occur in the first few weeks or months after surgery or cancer treatment. Whilst there are several effective treatments for lymphoedema there is currently no cure. It is therefore important for at risk individuals to try and reduce their risk of developing lymphoedema.
Reducing the risk of lymphoedema

It is thought that some things may trigger swelling of a limb(s) in individuals at risk of lymphoedema. It is important to reduce the risk of infection as the body response to this is the production of extra lymphatic fluid. An already damaged lymphatic system is unable to work efficiently and any extra fluid could overload it and lead to lymphoedema.

- **Look after your skin;** keep it clean and well moisturised reducing the risk of inflammation and infection. It is important to protect it from cuts and grazes, as well as insect bites and sunburn. If you notice any signs of infection see your GP as soon as possible.

- When removing body hair, **use an electric shaver**, rather than a razor blade to reduce the risk of cutting the skin. Depilatory creams may be used, but check that you are not sensitive or allergic to the cream first. Waxing should be avoided.

- **Avoid extreme temperatures.** Too much heat can increase the swelling so always test the water before you have a bath or shower. Avoid using saunas, hot tubs and steam rooms, and don’t sit too close to a fire or other heat source.

- If possible, **avoid having needles put into your affected limb(s)** when you have blood taken, injections, a drip (infusion), or acupuncture. Although there’s no strong medical evidence to support this, most lymphoedema experts think it’s a wise precaution to take to reduce the risk of infection. Don’t get a tattoo on the limb that is affected or at risk.

- **Look after your lymphatic system;** avoid items such as clothing, shoes or jewellery (depending on which limb or limbs are at risk) that are too tight or restrictive as they are likely to further impair lymphatic drainage.

- **Exercise and keep active;** exercise will help to stimulate the lymphatic system but should be done gently and gradually. Recommended exercises include brisk walking, swimming, light aerobics, cycling and yoga.

- **Keep to a healthy weight;** being overweight can increase the risk of developing lymphoedema so try to keep your weight within the normal range for your height.

**Further information**

If you would like further information on any of the above ways to help reduce the risk of lymphoedema ask a member of the medical team looking after you for advice.

**Contacts**

Skin Cancer Specialist Nurses: 01223 348156

**Acknowledgements**

The Lymphoedema Support Network: 020 7351 4480

Macmillan: 0808 808 00 00
We are now a smoke-free site: smoking will not be allowed anywhere on the hospital site.
For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Other formats:

If you would like this information in another language, large print or audio, please ask the department where you are being treated, to contact the patient information team: patient.information@addenbrookes.nhs.uk.

Please note: We do not currently hold many leaflets in other languages; written translation requests are funded and agreed by the department who has authored the leaflet.

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