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of Nursing

Reducing the risk of upper limb lymphoedema

Guidance for nurses in acute and community settings





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Acknowledgements

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Denise Hardy acknowledges information from the Lymphoedema Support Network's patient fact sheets in this work.

Available from www.lymphoedema.org

Published by the Royal College of Nursing, 20 Cavendish Square, London, W1G 0RN

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Introduction

One in nine women will develop breast cancer at some point in their lifetime. Lymphoedema can affect up to 28 per cent of all such patients and many women fear this often distressing and disabling condition more than the cancer itself. In most cases, the cancer can be cured; lymphoedema, however, can only be controlled, especially if it is not diagnosed early enough. This guidance will look at ways in which you can minimise the risks of lymphoedema developing in your patients.

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 a leg. It develops when the lymphatic drainage system is unable to work effectively because it has become damaged, overloaded or its function is impaired. This results in a build-up of fluid and other substances, such as protein and waste products, in the tissues. A swelling will develop when the lymph vessels cannot keep up with the extra demands on their drainage capacity.

In the early stages, the swelling may be soft to the touch and intermittent. For example, it may reduce overnight when the limbs are less dependent. Over time, the swelling becomes a more constant feature and may start to feel solid and thickened or fibrous. In these cases the limb can feel heavy, tight and uncomfortable and the skin can become dry and susceptible to infection. Fitting into clothing can be very difficult and frustrating for patients. If the swelling is cancer-related, it is a very visible reminder of a potentially life-threatening disease.

How does the lymphatic system work?

The lymphatic system plays a very important part in the way that the body functions for two reasons.

- It acts as a waste disposal unit to help drain away fluid, proteins and waste matter from the tissues.
- It is part of the body's immune system and contributes to the prevention of infection.

The lymphatic system is a one-way drainage system made up of channels or vessels of different sizes. They make a pathway all over the body, starting just underneath the surface of the skin and ending in the neck, where the lymph is emptied into the veins and back into the general circulation. The excess fluid and waste products will then be excreted from the body via the kidneys.

The initial drainage begins with a mesh-like network in the tissue spaces, known as initial lymphatics. Once tissue fluid enters the initial lymphatics, it becomes known as lymph. From here it moves along into larger and deeper lymphatics. These vessels are similar to veins in their structure and they contain valves and muscle which, with the help of the sympathetic nervous system, gently pulsate to push fluid along. Lymphatic drainage is also enhanced by muscle activity, so exercise and movement is important to maintain and optimise lymph drainage.

Lymph will pass through at least one lymph node on its journey to the neck and it is here where the lymph is filtered; waste products, proteins, etc., are removed and the lymph becomes more concentrated.

Causes of upper limb (arm) lymphoedema

Lymphoedema is known as primary or secondary lymphoedema, depending on the cause.

Primary lymphoedema is generally thought to be the result of a congenital or genetic abnormality of the lymphatic system before birth. Although this is mainly seen in people with leg lymphoedema, it can also occasionally cause swelling in the arm or elsewhere in the body.

Secondary lymphoedema results from damage to local lymphatic vessels and/or lymph nodes, or from an overload of fluid in the tissues that causes the lymphatic system to work less effectively.

Breast cancer and its treatment are known to be the biggest cause of upper limb lymphoedema, but it may also develop for the following reasons (MEP, 2006):

- **trauma or injury to the lymphatic system**, such as removal of lymph nodes (as in breast cancer surgery or malignant melanoma), radiotherapy to the armpit, neck or chest, burns to the arms or upper part of the body, or extensive scarring or large wounds on the arms or upper part of the body (front or back)
- **malignant disease** where the cancer is advanced and causes obstruction to the lymph nodes or vessels in the armpit, chest or neck
- **venous disease** such as deep vein thrombosis, or through extensive intravenous drug use
- **infection** such as cellulitis or erysipelas, lymphadenitis (where the lymph nodes are swollen, tender and painful), tuberculosis or filariasis (a parasitic infection transmitted by mosquitoes in certain African and Asian countries)
- **inflammation**, including rheumatoid arthritis and chronic skin conditions such as dermatitis or psoriasis
- **immobility or dependency of the arm** due to paralysis, stroke or multiple sclerosis.

Lymphoedema is usually of gradual onset and does not always occur in the first few weeks or months following surgery or cancer treatment. In some cases, it can develop many years later and, therefore, carries a lifelong risk.

Recognising the early signs and symptoms of upper limb lymphoedema

Early signs and symptoms of lymphoedema can include:

- clothing or jewellery (sleeves or rings) feeling much tighter than usual
- noticeable sensations of heaviness, stiffness, tightness or fullness in the arm, hand or shoulder
- the arm aching more than usual
- noticeable swelling, though initially this may come and go and will often be worse at the end of the day.

Due to its wide range of causes, lymphoedema can be seen in many different health care settings, including GP practices, nursing homes and hospital departments such as surgical units, dermatology departments and radiotherapy units. Moreover, patients often suffer with the disease because of a lack of understanding from health care providers about how to treat it. If health care professionals are able to recognise the early signs of lymphoedema, it is possible to minimise the risks of it developing or at least to treat it earlier rather than later.

Recognising the risk factors for upper limb lymphoedema

Sometimes, there are features that indicate that lymphoedema is more likely to occur. If these risk factors are identified early by health care professionals, it is easier to treat and the risk of occurrence can even be minimised.

Lymphoedema is sometimes more likely to occur in the case of:

- axillary node dissection
- radiotherapy to the breast and/or armpit, chest or neck
- trauma to an 'at-risk' arm (for example, by injection, blood pressure monitoring or blood sampling)
- scar formation, fibrosis or radiotherapy skin damage
- drain or wound complications, or infections after surgery
- 'cording' (the appearance of tender, painful cord-like structures below the skin, usually from the armpit to the elbow), often known as 'axillary web syndrome'.

This is thought to be inflammation or thrombosis of the lymph vessels

- seroma formation (an accumulation of fluid at, or near, the surgical wound), particularly if this has had to be drained frequently
- obesity (being overweight can put added strain onto an impaired lymphatic system)
- history of primary lymphoedema in the family
- ongoing chronic skin disorders, such as hand or arm eczema or psoriasis
- axillary or subclavian vein thrombosis
- living in or visiting an area where filariasis is common
- advanced cancer.

Reducing the risk

Cellulitis (infection of the skin/tissues) is a serious complication in a limb that is already affected by lymphoedema, but it is also a risk factor for the development of lymphoedema in breast cancer patients. It is categorised as an acute, spreading inflammation of the skin and subcutaneous tissues and is associated with pain, swelling and erythema. Some episodes are accompanied by severe systemic upset, with high fever and rigors; others are milder, with minimal or no fever. Increased swelling of the affected area may occur and inflammatory markers (CRP, ESR or PV) may be raised. It is difficult to predict a response to treatment but it is therefore very important to try to avoid it in the 'at risk' arm as it could trigger the onset of lymphoedema.

Cellulitis should be treated immediately using appropriate antibiotics (BLS and LSN, 2010).

For more information on the management of cellulitis in lymphoedema, visit www.lymphoedema.org/lsn

There are a number of other ways to maintain skin integrity and reduce risk to an 'at risk' limb.

- Unless there is a medical emergency, avoid taking blood pressure measurements, injections or blood samples from the 'at risk' limb as this may lead to infection and/or the onset of lymphoedema. This is

also the case in people who already have lymphoedema. For women who have had bi-lateral surgery or radiotherapy, blood samples may be obtained from other areas of the body, such as the feet or legs (RCoA, 2008).

- Keep the 'at risk' limb spotlessly clean. Soapless cleansers (e.g., aqueous cream, soap substitutes such as Oilatum or Neutrogena 'soap' bars, or an E45 wash) are recommended to prevent the skin from drying out. The skin should be dried carefully, especially between the fingers.
- It is very important to keep the skin supple; never allow the skin to become dry or flaky. A moisturising cream should be applied on a daily basis.
- Avoid cuts, scratches or bites to the 'at risk' limb. Care should be taken when cutting nails; do not cut the cuticle or push back too hard as this can cause an injury and allow bacteria to enter, thus leading to infection. Use antiseptic solution immediately on cuts, etc., to prevent infection.
- Encourage the use of an electric razor, rather than a wet shave, to reduce the risk of cutting the skin. Depilatory (hair-removing) creams may also be used if there are no sensitivities to the product. Waxing should be avoided.
- Sunburn should be avoided – encourage the use of a high factor sunscreen (at least SPF 25).
- Encourage the use of insect repellent containing at least 50 per cent DEET to prevent bites, and use mosquito nets in countries where lymphatic filariasis is common.
- Saunas and hot baths should be avoided – the 'at-risk' limb should be kept as cool as possible.
- Restrictive clothing and tight jewellery should be avoided as this can further impair lymphatic drainage. Encourage well-fitting, supportive bras that are not too tight around the ribs or over the shoulders. A well-measured bra with wide shoulder and side straps will help prevent swelling in the breast area.
- Encourage a healthy, well-balanced diet to keep weight within normal limits. Low protein/salt diets should be avoided as these do not help to reduce lymphoedema. Fluid intake should also be encouraged (plenty of water is recommended).
- The limb should be used normally; encourage gentle, regular exercise. Swimming, t'ai chi, Pilates and yoga are very good forms of exercise to improve lymphatic drainage and prevent joint and muscle stiffness. Prompt referral to a physiotherapist should be sought if problems with function or mobility persist. The limb should not ache with tiredness following exercise.
- Activities which put a heavy strain on the 'at-risk' arm should be avoided. These include moving furniture, picking up or carrying heavy weights (such as shopping or children), working at heavy gardening tasks such as digging, and DIY activities.
- During long flights, gentle exercise should be carried out, such as clenching and unclenching the fists and shrugging the shoulders.

Using exercise to help reduce the risk of developing lymphoedema

Exercise is important to maintain and improve lymphatic drainage and should be started as soon as possible after breast surgery (including axillary node dissection). However, recent research suggests that arm movements should be restricted to below shoulder level for the first seven days to reduce the incidence of arm lymphoedema; after that, full range of movement is encouraged (Todd et al, 2008). Referral to breast care nurses, physiotherapists and lymphoedema specialists will be helpful in providing specific and relevant exercise programmes.

Points to remember during exercise

- Movements should initially be slow, rhythmical, gentle and well controlled to improve muscle tone and joint mobility.
- Exercises should include a gentle range of movement that bends and stretches each joint.
- Deep breathing exercises are extremely helpful for relaxation and improving the body's lymph drainage.
- Specific, daily exercise should continue on a regular basis for up to one year to prevent scar tissue forming and to help keep normal function of the arm.
- Keep-fit activities, use of heavy weights and participation in aerobic exercises should be gradually implemented – gradual build up of strength, resistance and stamina is recommended.
- A 'warm up' and 'cool down' should be incorporated before and after exercise. In most cases, patients will still be able to perform the exercises they enjoy, although they may need time to build up to their previous level of exercise.

What to do if swelling develops

The above information will help to minimise the risk of lymphoedema developing. However, any swelling in the hand, arm or breast should be reported immediately to the breast care nurse or lymphoedema specialist. It is also important to report any pain, discomfort, sudden inflammation (reddening of the skin, accompanied by localised swelling) or reduced movement of the 'at-risk' arm or shoulder. A sensation of having a tight cord pulling from the armpit to the elbow or hand (known as cording) should also be reported.

Prompt referral to a lymphoedema clinic will ensure that the appropriate assessment and essential treatment can take place. Lymphoedema can be greatly improved, and effectively controlled and managed, especially if it is reported as soon as possible after onset.

References

British Lymphology Society and the Lymphoedema Support Network (2010) *Consensus document on the management of cellulitis in lymphoedema*, London: BSL and LSN. Available at: www.lymphoedema.org

Medical Education Partnership (2006) *Best practice for the management of lymphoedema. International Consensus*, London: MEP Ltd.

Patient Liason Group (PLG) within The Royal College of Anaesthetists (2009) *Breast cancer related lymphoedema – information for Doctors on Patients with lymphoedema*
[www.roac.ac.uk/docs/lymphoedema doctors.pdf](http://www.roac.ac.uk/docs/lymphoedema%20doctors.pdf)

Todd J, Scally A, Dodwell D, Horgan K and Topping A (2008) A randomised controlled trial of two programmes of shoulder exercise following axillary node dissection for invasive breast cancer, *Physiotherapy*, 94 (4), pp. 265-273.

Further reading

Twycross R, Jenns K and Todd J (eds) (2000) *Lymphoedema*, Oxford: L Radcliffe Medical Press.

Lymphoedema Support Network, Factsheets: *Reducing the risk of upper limb lymphoedema; Skin care for people with lymphoedema; Recreational exercise with lymphoedema; Management of cellulitis in lymphoedema*. Fact sheets are available to order from the Lymphoedema Support Network (LSN) at St Luke's Crypt, Sydney St, London SW3 6NH or telephone: 020 7351 0990.

Mortimer P and Todd J (eds) (2007) *Lymphoedema: advice on self-management and treatment* (3rd edition), Beaconsfield: Beaconsfield Publishers.

Burt J and White G (1999) *Lymphedema: a breast cancer patient's guide to prevention and healing*, USA: Hunter House Publishing.



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September 2011

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www.rcn.org.uk

RCN Direct
www.rcn.org.uk/direct
0345 772 6100

Published by the Royal College of Nursing
20 Cavendish Square
London
W1G 0RN

020 7409 6100

Publication code 004 138

ISBN 978-1-906633-83-7