

Reducing the risk of lymphoedema



This factsheet describes what lymphoedema is and how you might reduce your risk of developing it. This factsheet aims to give you a better understanding of the condition and enable you to discuss any questions you might have with your cancer specialist or breast care nurse.

What is the lymphatic system?

The lymphatic system is made up of a network of small vessels (similar to blood vessels), groups of lymph glands (nodes) that extend throughout the body (which the vessels are connected to), and other lymphatic tissue such as the tonsils, liver and spleen. The lymphatic vessels transport a colourless fluid called lymph, which is made up of water, protein and other substances. It also contains white blood cells called lymphocytes that help your body fight infection.

Lymph flows very slowly but continuously through the lymph vessels to the lymph nodes, which are situated all over the body, where the lymph is filtered. The lymph nodes also help fight infection by filtering out waste products like bacteria. The lymphatic system works with the blood system to maintain and protect the balance of fluid in the surface tissues of the body by draining, filtering and transporting lymphatic fluid around the body.

What is lymphoedema?

Lymphoedema can be a distressing side effect of breast cancer and its treatments. Lymphoedema is a swelling caused by a build-up of lymph fluid in the tissues. This build-up is usually a result of damage to the lymphatic system because of surgery and/or radiotherapy to the lymph nodes in the axilla (armpit) and surrounding areas, such as the neck or chest.

Lymphoedema can occur weeks or months following surgery or radiotherapy. It can also develop much later, sometimes many years after treatment. Occasionally it can also be caused by cancer cells invading the lymph nodes.

Lymphoedema is a long-term condition which means that it can be controlled, but it will never completely go away.

Lymphoedema affects people in different ways. The most common symptom is swelling of the arm including the hand and fingers. Swelling can also affect the breast, chest, shoulder, or the area behind the armpit. The skin feels stretched making it difficult to move the arm. In some the swelling may result in aching, heaviness or a pins-and-needles sensation. Some people may experience symptoms such as heaviness or aching of the arm but no swelling.

Who is at risk?

It is estimated that a quarter to a third of people who have surgery and/or radiotherapy to the armpit as part of their treatment for breast cancer go on to develop lymphoedema at some time in their life. This figure will be less for people who have sentinel lymph node biopsy of the armpit, as this is less traumatic to the lymph system.

However, as sentinel node biopsy is a relatively new procedure it is still not clear how people's risk of lymphoedema will be affected by this procedure in the long term.

It is not yet known why some people develop this condition and others don't. The vast majority of people who develop lymphoedema after breast cancer and its treatment have only mild to moderate symptoms. It is only the arm, hand and fingers on the same side as the affected breast that become 'at risk'.

Can I reduce my risk of lymphoedema?

While it is not known exactly what causes lymphoedema, an infection or injury to your 'at risk' arm may slightly increase your chances of developing it. The following advice may help to protect your arm and hand and therefore reduce your risk.

- Gentle exercise such as swimming or walking will keep your joints supple and is important for lymph drainage. Your breast care nurse will give you some exercises to help your recovery following surgery. It is important to build up exercise gradually, avoid over-tiring your muscles and stop if you notice any pain or swelling.
- Look after the skin on your 'at risk' arm. Wash it every day avoiding soaps that dry out the skin. Try not to use very hot or cold water. It may also be helpful to avoid very hot saunas or steam rooms. Dry your arm and hand thoroughly and use a moisturising cream, such as aqueous cream, to help keep the skin supple and moist. Any moisturiser that prevents your skin from becoming dry and flaky can be used.
- If possible, avoid having your blood pressure or blood samples taken from your 'at risk' arm. Also avoid having acupuncture and injections into the

arm. If both your arms are affected then your blood pressure or blood samples may be taken from your legs or feet. It may not always be possible to avoid having injections in your 'at risk' arm, for example sometimes during a course of chemotherapy. It is important to discuss this with your chemotherapy nurse or oncologist if it is a concern for you.

- Some of the health care professionals you come into contact with may not be aware of avoiding your affected arm so you may have to tell them. The Lymphoedema Support Network (contact details at the end) produces a bracelet to wear on your affected arm to remind you and others to be careful.
- Avoid having deep-tissue massage to your 'at-risk' arm unless the practitioner is trained to work with people who have, or are at risk of, lymphoedema. However, there is no need to avoid massage altogether.
- Try to avoid cuts, scratches, insect bites or stings on your 'at risk' arm. Wear protective gloves for gardening or washing up, oven gloves when cooking and a thimble when sewing. Use insect repellent when appropriate.
- Avoid biting your nails. Use a nail file and take care to avoid damage to the cuticles, as this can allow bacteria to enter and cause infection.

- Avoid getting sunburnt. Use a sunscreen with a high sun protection factor (SPF) of 15 or above and remember to apply it even under clothing as it is possible to become sunburnt through certain clothing.
- Take care when removing unwanted hair in your armpit. Using a well maintained electric razor is the safest method. Waxing is not recommended because it can cause damage to the skin and might increase the risk of infection. Depilatory (hair removal) creams may be used with caution and it is advisable to do a patch test first to check for skin reactions. Remember that the area may be numb, meaning you will not feel any soreness or reaction as it develops, so take care when applying the cream and always follow the instructions.
- Avoid constriction around the arm and armpit from tight fitting bras, sleeves and clothing or heavy shoulder bags. Also ensure watches, rings and bracelets are not too tight.
- Try not to strain with activities such as pushing or pulling, digging the garden or heavy lifting such as carrying heavy shopping bags.
- During long journeys, gently exercise your arm as much as possible. If you are standing on a train or a bus, try not to hold on with your 'at risk' arm.

- If you are planning to take a long haul flight, you may like to discuss the possibility of being fitted for a compression sleeve. However, you may be interested to know that there has not been much research in this area and some specialists believe this precaution is not necessary. Our **Living with lymphoedema after breast cancer** booklet has more information on compression sleeves.

- Try to maintain a healthy body weight by taking regular exercise and following a balanced diet. See our factsheet **Diet and breast cancer** for information.

What should I do if I damage my skin?

As infection or injury to your 'at risk' arm may slightly increase your chances of developing lymphoedema, the following tips may be useful.

- Treat any scratches, grazes, cuts or insect bites promptly. Clean the area and apply an antiseptic solution or cream to help prevent an infection.
- If you notice a rash or your arm becomes red and painful, contact your GP as soon as possible, as you may have an infection that needs immediate treatment with antibiotics.

- If you are travelling abroad, you may want to ask your GP if they would consider prescribing you a course of antibiotics to take with you, in case you develop signs of an infection in your affected arm/hand. This may be particularly helpful if you are travelling to a country where rapid access to good quality healthcare is difficult.

What should I do if I notice symptoms?

If you notice any swelling of your arm, hand, fingers, breast or chest wall, contact your breast care nurse or hospital specialist as soon as possible. If you are no longer in touch with your hospital team, you should approach your GP with your concerns and they can refer you to the hospital.

If you do develop lymphoedema, its symptoms respond well to treatment and can be controlled and improved in most cases, especially if treatment is started when the symptoms are mild. For information on treatments, see our booklet **Living with lymphoedema after breast cancer**.

Further help from Breast Cancer Care

For further medical information, emotional support, and details of our services, call our helpline free on **0808 800 6000** (for Typetalk prefix **18001**).

Breast Cancer Care's website has an email enquiries service called Ask the nurse, along with forums and live chat sessions where you can share your views with people in a similar situation. For more information about these services and other online support, visit **www.breastcancercare.org.uk**

We run courses and activities for people with breast cancer, which aim to provide information and support and give people the chance to meet others in a similar situation. For more information about these events, call our helpline or contact your nearest Breast Cancer Care centre (details on the reverse).

Breast Cancer Care also has a wide range of publications to guide you from diagnosis to living well after treatment. You can download and order our publications at **www.breastcancercare.org.uk** or call our helpline on **0808 800 6000** for a printed order form.

Other organisations

Macmillan Cancer Support

89 Albert Embankment
London SE1 7UQ

Telephone: 020 7840 7840

Macmillan CancerLine: 0808 808 2020

Cancerbackup Helpline: 0808 800 1234

Textphone: 0808 800 0121

Email: cancerline@macmillan.org.uk

Website: www.macmillan.org.uk

Macmillan Cancer Support improves the lives of people affected by cancer by providing practical, medical, emotional and financial support, and campaigning for better cancer care. Their Cancerbackup Helpline team can provide up-to-date information on diagnosis, symptoms, treatments, clinical trials and more. The Macmillan CancerLine provides information and emotional support. Other services include cancer information booklets, Macmillan nurses and a website.

Useful organisations

Breast Cancer Haven

Effie Road
London SW6 1TB
Telephone: 020 7384 0099
Website: www.breastcancerhaven.org

Breast Cancer Haven is a charity offering a free programme of care to help breast cancer patients and those supporting them. Breast Cancer Haven produces a DVD 'Lymphoedema awareness: reducing your risk'. If you would like a copy, please call 020 7384 0000 or email websales@breastcancerhaven.org.uk

British Lymphology Society

9-11 Oldbury Road
Cheltenham
Gloucestershire GL51 0HH
Telephone: 01242 695077
Email: info@thebls.com
Website: www.thebls.com

The British Lymphology Society (BLS) is a multi-disciplinary group of healthcare professionals and other interested parties directly involved in the management of lymphoedema or interested in furthering the work of the Society. The main objectives of BLS are to promote awareness of lymphoedema and to establish standards of treatment and long-term management of this condition. Its website includes a

directory of lymphoedema treatment services around the country.

Lymphoedema Support Network

St Luke's Crypt, Sydney Street
London SW3 6NH
Administration: 020 7351 0990
Information and support: 020 7351 4480
Email: adminlsn@lymphoedema.freemove.co.uk
Website: www.lymphoedema.org/lsn

The Lymphoedema Support Network (LSN) is a national charity which was founded in 1991 by a group of people with lymphoedema. The charity provides information and support to people with lymphoedema. It runs a telephone helpline, produces a quarterly newsletter, a wide range of factsheets, self-help videos and maintains an up-to-date website. It works to raise awareness of lymphoedema and campaigns for better standards of care.

This factsheet has been produced by Breast Cancer Care's clinical specialists and reviewed by healthcare professionals and people affected by breast cancer.

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Registered charity in England and Wales 1017658
Registered charity in Scotland SC038104
Registered company in England 2447182

Central Office

Breast Cancer Care

5-13 Great Suffolk Street
London SE1 0NS
Telephone 0845 092 0800
Fax 0845 092 0820
Email info@breastcancercare.org.uk

Centres

London and the South East of England

Telephone 0845 077 1895
Email src@breastcancercare.org.uk

Wales, South West and Central England

Telephone 0845 077 1894
Email cym@breastcancercare.org.uk

East Midlands and the North of England

Telephone 0845 077 1893
Email nrc@breastcancercare.org.uk

Scotland and Northern Ireland

Telephone 0845 077 1892
Email sco@breastcancercare.org.uk

About Breast Cancer Care

Breast Cancer Care is here for anyone affected by breast cancer. We bring people together, provide information and support, and campaign for improved standards of care. We use our understanding of people's experience of breast cancer and our clinical expertise in everything we do. Visit www.breastcancercare.org.uk or call our free helpline on **0808 800 6000**.

Calls may be monitored for training purposes. Confidentiality is maintained between callers and Breast Cancer Care.

Donations from the public make it possible for us to provide publications like this one free to people affected by breast cancer.

If you would like to make a donation, please send your cheque to: Breast Cancer Care, RRKZ-ARZY-YCKG, 5-13 Great Suffolk Street, London SE1 0NS. Or donate via our website at www.breastcancercare.org.uk