Reducing the risk of lymphoedema



This booklet describes what lymphoedema is and how you might reduce your risk of developing it. We hope it helps you to understand more about lymphoedema and discuss any concerns you have with your specialist team.

If you have already developed lymphoedema, you may like to read our booklet Living with lymphoedema after breast cancer.

This information is by Breast Cancer Care.

We are the only specialist UK-wide charity that supports people affected by breast cancer. We've been supporting them, their family and friends and campaigning on their behalf since 1973.

Today, we continue to offer reliable information and personal support, over the phone and online, from nurses and people who've been there. We also offer local support across the UK.

From the moment you notice something isn't right, through to treatment and beyond, we're here to help you feel more in control.

For breast cancer care, support and information, call us free on 0808 800 6000 or visit breastcancercare.org.uk



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6 Call our Helpline on 0808 800 6000

What is lymphoedema?

Lymphoedema is swelling of the arm, hand or breast/chest area caused by a build-up of lymph fluid in the surface tissues of the body. It can occur as a result of damage to the lymphatic system, for example because of surgery or radiotherapy to the lymph nodes under the arm (axilla) and surrounding area.

Although it affects people in different ways, the most common symptom of lymphoedema is swelling of the arm, which can include the hand and fingers on the affected side. Swelling can also affect the breast, chest, shoulder or the area on the back behind the armpit.

One, some or all of the lymph nodes under the arm can be removed during breast surgery to check whether any cancer cells are present. The lymph nodes and vessels that have been damaged or removed cannot be replaced, so the lymphatic drainage routes are reduced or altered. This can cause lymph fluid to build up in the surrounding tissues. It's not fully understood why lymphoedema develops in some people and not others.

Lymphoedema may develop soon after surgery, radiotherapy or chemotherapy, but it can also occur many years later and may be triggered by infection or injury. There's a lifetime risk of developing lymphoedema following breast cancer treatment where the lymph nodes have been removed or damaged. Sometimes lymphoedema can be due to cancer cells blocking the lymph system.

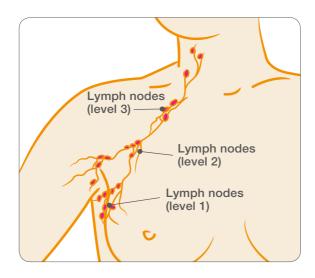
Lymphoedema is a long-term condition, which means that once it has developed it can be controlled but is unlikely to ever go away completely. Symptoms may be mild, moderate or severe. Treatment is aimed at encouraging other healthy parts of the lymph system to work more effectively and to prevent further problems or complications. The symptoms of lymphoedema usually respond well to treatment and this means that in most cases it can be controlled.

What is the lymphatic system?

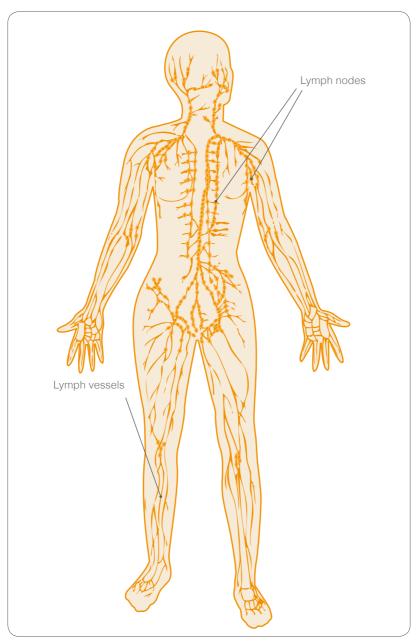
The drainage and filtering system of the body is made up of lymph nodes (also called lymph glands), vessels and fluid. It helps to get rid of waste products and fight infection.

The lymphatic vessels transport a straw-coloured fluid called lymph which flows slowly but continuously through the lymph vessels to the lymph nodes where it is filtered. Lymph is made up of water and protein and also contains white blood cells called lymphocytes, which help your body fight infection.

The lymph nodes help fight infection by filtering out waste products like bacteria. They can also filter out cancer cells that have spread from a breast cancer, destroying some of them in the process.



The lymphatic system



What are the physical symptoms of lymphoedema?

Lymphoedema symptoms can vary, and many people who develop lymphoedema only have mild symptoms that can be well controlled. It's important to get advice from your specialist team as soon as you notice any swelling affecting the hand/fingers, arm or breast/chest area.

Swelling

Swelling often develops in the arm or chest area immediately after breast surgery. This is part of the healing process and usually settles within a short time without any treatment, but it's important this is assessed by your specialist team as soon as possible. Swelling to your hand, arm, breast or chest that develops later on, or after your cancer treatment is completed, could be a sign of lymphoedema. The swelling may initially come and go and will often be worse towards the end of the day, or after strenuous activities. You may notice that clothing (particularly your bra) and jewellery (especially rings and bracelets) feel much tighter than usual.

Tightness

The arm or breast can feel tight when there is extra fluid in the tissues. Some people feel tightness in the arm without the arm appearing swollen. Gentle exercise may help to relieve any feelings of tightness.

Dry skin

Where there is swelling the skin is stretched and can become dry and flaky and sometimes feel itchy. Dry, cracked skin increases the risk of cellulitis (a sudden infection of the skin and the tissue underneath it).

Discomfort

Some people experience discomfort with lymphoedema. A dull ache or heaviness in the arm, breast or chest area (the same side of the site of cancer) can also be an early sign of lymphoedema.

Who is at risk?

People having surgery and/or radiotherapy to the armpit (axilla) may develop lymphoedema at some time in their life. The risk is greater if you've had both of these treatments to the lymph nodes under the arm. The arm, hand, fingers, breast and chest wall only on the same side as the affected breast are at risk of developing swelling.

There is strong evidence to suggest that being overweight can increase your risk of developing lymphoedema due to added strain on an already weakened lymphatic system (see 'Maintaining a healthy body weight' below).

People who have a sentinel lymph node biopsy (to identify whether or not the first lymph node/s is clear of cancer cells) have a reduced risk of developing lymphoedema compared to people who have surgery where a greater number of lymph nodes are removed.

Most people who have had the lymph nodes under their arm removed don't develop lymphoedema. However, it's important to be aware of the risk and guickly deal with any swelling that develops.

How can I reduce my risk of lymphoedema?

While it's not known exactly what causes lymphoedema, damage to the skin or injury to your 'at risk' arm can lead to cellulitis which increases your risk of developing lymphoedema. Some of the following may also help.

Maintaining a healthy body weight

Eat healthily and, where appropriate, lose weight to reduce the strain on your body in general and specifically the strain on your lymphatic system. See our booklet **Diet and breast cancer** for more information. Regular physical exercise will also help with maintaining a healthy body weight.

Using your 'at risk' arm and regular exercise

You are more likely to increase your risk by overly protecting your arm and not using it enough. Try to use your arm normally but don't over-use it to the point where it aches and feels heavy.

- If you have recently had breast surgery, you should follow the exercises provided by your specialist team to help your recovery, and gradually return to normal activity. Our leaflet Exercises after breast **cancer surgery** contains arm and shoulder exercises to increase mobility after surgery, and help reduce the risk of lymphoedema.
- Exercising the arm regularly can help, and you should be able to return to any sporting activities you did before your surgery. However, if you haven't been doing these activities regularly you will need to gradually build up your arm strength. Unless you are used to regularly lifting heavy loads, ask for help carrying luggage or heavy shopping, or when moving furniture.
- It's best to take regular breaks while doing household chores, particularly repetitive actions like ironing and cleaning windows with your 'at risk' arm, as these activities will put more strain on your arm.
- Deep breathing exercises can improve lymph drainage.

Protect your skin

Infection in your 'at risk' arm, hand or breast can cause swelling, and may damage your lymphatic system, leading to lymphoedema. The following tips can help reduce your risk of developing an infection.

- Moisturising the affected area/s daily will help prevent dry and cracked skin. This allows your skin to protect you against infection and can reduce any damage to the skin. Use a moisturising cream that suits vour skin type.
- Where possible, protect against damage to the skin. Use sunscreen to avoid sunburn, use oven gloves when cooking, apply insect repellent, wear protective gloves in the garden (particularly when near rose bushes or brambles) and take care when cutting your nails.
- If you have a cut or a graze, keep it clean and use antiseptic cream. If you notice any signs of infection (redness, heat, tenderness or swelling) contact your GP as you may need antibiotics.

While there is no strong evidence to support them the precautions below may help reduce the risk of developing lymphoedema.

- Wear comfortable clothing and avoid tight-fitting jewellery.
- Take care when removing hair from under your arm. Waxing and razor blades can damage the skin and increase your risk of infection. Electric razors are gentler on the skin. Depilatory (hair removal) cream can be used, but check first that you are not sensitive or allergic to the cream.
- Take care when carrying heavy shoulder bags.
- Hot baths, saunas and steam rooms may put extra strain on your lymphatic system, so you might not want to use them regularly, or avoid them altogether.
- Deep tissue massage and heat therapy will encourage more fluid to the treated area so you may want to avoid this on your 'at risk' side. However, many practitioners are now trained to work with people who have, or are at risk of, lymphoedema, so check with your therapist.

Can I have an injection, blood taken, or blood pressure taken from the 'at risk' arm?

There are different opinions among healthcare professionals about using the 'at risk' arm for these procedures.

There is no strong evidence to suggest that taking blood or taking a blood pressure reading from your 'at risk' arm will cause lymphoedema, but current recommendations are that the unaffected arm should be used whenever possible.

- Injections into a vein (for example, chemotherapy) will usually be given into the unaffected arm. When that is not possible, your clinician may consider a central venous line for multiple injections, or the 'at risk' arm if a limited number of injections will be given.
- Injections into the muscle will probably be given into the unaffected arm or another suitable part of the body.
- Blood tests will usually be taken from the unaffected arm.
- If possible use the unaffected arm for blood pressure readings. These readings can be taken from your leg if both arms are affected.

Travel

When travelling you may want to consider the following.

- During flights or long train/car journeys, do gentle exercises such as clenching and unclenching your fist and shrugging your shoulders.
- Protect against insect bites by using insect repellent (at least 50%) DEET) and, where appropriate, a mosquito net.
- Carry antiseptic cream for cuts and grazes.
- If you are travelling to a country where quick access to good quality medical care is difficult, ask your GP for a course of antibiotics to take with you in case of infection. If you develop signs of infection in your 'at risk' arm or hand, treat the infection as early as possible.

There is no evidence that air travel or cabin pressure triggers lymphoedema, or that wearing a compression sleeve (usually used by people with lymphoedema) will help to prevent swelling. In fact, an ill-fitting sleeve may cause more problems.

What should I do if I notice swelling?

If you notice any swelling in your arm, hand, fingers, breast or chest wall, contact your breast care nurse or specialist team as soon as possible. Tell them if you notice any pain, discomfort or reddening of the skin. They can assess your symptoms and in many cases the breast care nurse at your hospital will be able to help and advise you about mild lymphoedema. If you have had swelling for some time, or you have other symptoms, you may need to be referred to a specialist lymphoedema service for advice and treatment. If you're no longer in touch with your hospital team, talk to your GP and ask for a referral to a lymphoedema service.

Early diagnosis of lymphoedema makes it easier to treat. Lymphoedema can often be controlled and relieved. The aim of treatment for lymphoedema is to encourage lymph fluid to move away from the swollen area, to try and improve the physical symptoms and to stop them getting worse. For information on treatments, see our booklet Living with lymphoedema after breast cancer.

What should I do if I notice any signs of infection?

Infection causes redness or a rash, heat, swelling and tenderness or pain, and damages the lymphatic system. Contact your GP or breast care nurse as soon as possible if you experience these symptoms as you may need antibiotic treatment.

If you notice a cut, graze, scratch or insect bite, keep the area clean and apply antiseptic cream, covering the area where appropriate. Contact your GP if you think the area has become infected.

Further support

If you have any concerns about your risk of lymphoedema, you can talk to your specialist or breast care nurse. You can also call Breast Cancer Care on 0808 800 6000 (Text Relay 18001) or visit our website breastcancercare.org.uk



4 ways to get support

We hope this information was helpful, but if you have questions, want to talk to someone who knows what it's like or want to read more about breast cancer, here's how you can.



Speak to trained experts, nurses or someone who's had breast cancer and been in your shoes. Call free on 0808 800 6000 (Monday to Friday 9am–5pm, Wednesdays til 7pm and Saturday 9am–1pm).



Chat to other women who understand what you're going through in our friendly community, for support day and night. Look around, share, ask a question or support others at forum.breastcancercare.org.uk



Find trusted information you might need to understand your situation and take control of your diagnosis or order information booklets at breastcancercare.org.uk



See what support we have in your local area. We'll give you the chance to find out more about treatments and side effects as well as meet other people like you.

Visit breastcancercare.org.uk/in-your-area

Other organisations

The Lymphoedema Support Network St Luke's Crypt Sydney Street London SW3 6NH

Administration: 020 7351 0990

Information and support: 020 7351 4480

Email: admin@lsn.org.uk

Website: www.lvmphoedema.org

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

British Lymphology Society (BLS) 24 Kiniths Crescent West Bromwich B71 4BX

Telephone: 01452 790 178 Website: www.thebls.com

The British Lymphology Society (BLS) is a multidisciplinary 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 the condition. Its website includes a directory of lymphoedema clinics around the country.

The Haven Effie Road London SW6 1TB

Telephone: 020 7384 0099 Website: www.thehaven.org.uk

The Haven is a charity offering a free programme of care to help breast cancer patients and those supporting them. The Haven produces a DVD, Lymphoedema Awareness: Reducing your risk. If you would like a copy, call 020 7384 0000 or email info@thehaven.org.uk

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We're here for you: help us to be there for other people too

If you found this booklet helpful, please use this form to send us a donation. Our information resources and other services are only free because of support from people such as you.

We want to be there for every person facing the emotional and physical trauma of a breast cancer diagnosis. Donate today and together we can ensure that everyone affected by breast cancer has someone to turn to.

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We might occasionally want to send you more information about our services and activities
Please tick if you're happy to receive email from us Please tick if you don't want to receive post from us

We won't pass on your details to any other organisation or third parties.

5-13 Great Suffolk Street, London SE1 0NS

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About this booklet

Reducing the risk of lymphoedema was written by Breast Cancer Care's clinical specialists, and reviewed by healthcare professionals and people affected by breast cancer.



For a full list of the sources we used to research it:

Phone 0345 092 0808 Email publications@breastcancercare.org.uk



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When you have breast cancer, everything changes. At Breast Cancer Care, we understand the emotions, challenges and decisions you face every day, and we know that everyone's experience is different.

For breast cancer care, support and information, call us free on 0808 800 6000 or visit breastcancercare.org.uk

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