Reducing the risk of lymphoedema

This booklet describes what lymphoedema is and how you might reduce your risk of developing it after treatment for 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
What is lymphoedema?

Lymphoedema is swelling caused by a build-up of fluid in the body’s tissues. The swelling commonly affects the arm and can include the hand and fingers. Swelling can also affect the breast, chest, shoulder or the area on the back behind the armpit.

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 and surrounding area. Lymphoedema only affects the side of the body that was treated.

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.

The lymphatic system

The lymphatic system helps the body get rid of waste products and also fights infection. It’s made up of lymph nodes, also called lymph glands, and tiny tubes called lymph vessels.

The vessels transport a fluid called lymph to the lymph nodes. The lymph nodes filter out waste products and bacteria. They can also filter out cancer cells that have spread from a breast cancer.
What causes lymphoedema?

Some people develop lymphoedema after surgery or radiotherapy to the lymph nodes under the arm and surrounding area.

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.

Lymph nodes and vessels that are damaged or removed cannot be replaced. This can affect the lymphatic system’s ability to drain fluid in this area, and lymph fluid can build up in the surrounding tissues.

It’s not fully understood why lymphoedema develops in some people and not others, but people who have more lymph nodes removed may be at higher risk.

Sometimes lymphoedema can be due to cancer cells blocking the lymphatic system.

Lymphoedema may develop soon after surgery, radiotherapy or chemotherapy, but it can also occur many years later and may be triggered by a skin infection (cellulitis) or possibly injury.

Who is at risk?

You may be at risk of lymphoedema if you:

- have had surgery to the lymph nodes
- have had radiotherapy to the lymph nodes
- are overweight
- have limited arm mobility
- have had cellulitis (a sudden infection of the skin and the tissue underneath it)

The risk is greater if you’ve had both surgery and radiotherapy to the lymph nodes.

The risk is lower in people who only have a sentinel lymph node biopsy. This procedure identifies whether the sentinel lymph node (the first lymph node that the cancer cells are most likely to spread to) is clear of cancer cells.

There’s strong evidence that being overweight can increase your risk of developing lymphoedema because of added strain on an already
weakened lymphatic system (see 'Maintain a healthy body weight' on page 7).

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

**Symptoms of lymphoedema**

Lymphoedema symptoms can vary, and many people who develop lymphoedema have only mild symptoms that can be well controlled.

It’s important to get advice from your treatment team as soon as you notice any of the following symptoms.

**Swelling**

The most common symptom of lymphoedema is swelling.

While swelling in the arm or chest area often develops immediately after breast surgery, this is part of the healing process and usually settles without any treatment. However, it’s important to get any swelling assessed by your treatment 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:

- come and go to begin with
- be worse towards the end of the day
- be worse after strenuous activities or in hot weather

Clothing (particularly your bra) and jewellery (especially rings and bracelets) may 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.
Discomfort

Discomfort can be an early sign of lymphoedema. Some people experience:

- a dull ache
- heaviness in the arm, breast or chest area
- tingling
- numbness

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).

Arm stiffness

If your arm is swollen, it may limit movement in the joints.

How can I reduce my risk of lymphoedema?

Maintain a healthy body weight

Eat healthily and, if you need to, lose weight to help 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 about healthy eating.

Regular physical activity will also help with maintaining a healthy body weight.

If you’re unsure about the level of exercise you’re able to do, or would like guidance on a diet appropriate for you, your GP, practice nurse or pharmacist may be able to help you.

Using your ‘at risk’ arm and regular exercise

Try to use your arm normally. You’re more likely to increase your risk of lymphoedema by overly protecting your arm and not using it enough.
If you’ve recently had breast surgery, do the exercises provided by your treatment 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’ll need to gradually build up your arm strength. You may need to ask for guidance from your treatment team first.

Unless you’re used to regularly lifting heavy loads, ask for help carrying luggage or heavy shopping, or when moving furniture.

Deep breathing exercises can improve lymph drainage. You can find more information and tips on the Cancer Research UK website [cancerresearchuk.org](http://cancerresearchuk.org).

**Reduce your risk of infection**

Infection in your ‘at risk’ arm, hand or breast/chest area can cause swelling, and may damage your lymphatic system, leading to lymphoedema.

The following tips can help reduce your risk of developing an infection:

- moisturise the skin daily to prevent dry and cracked skin (use a moisturising cream that suits your skin type)
- use a high factor sunscreen to avoid sunburn
- use oven gloves when cooking
- apply insect repellent to avoid bites and stings
- wear protective gloves in the garden (particularly when near rose bushes or brambles)
- take care when cutting your nails
- take care if using wax or a razor to remove hair from under your arm as it can damage the skin. Electric razors are gentler on the skin. Depilatory (hair removal) cream can be used, but check first that you’re not sensitive or allergic to the cream
- keep any cuts or grazes clean and use antiseptic cream; contact your GP or breast care nurse if you think it has become infected
Other precautions

While there is no strong evidence to support them, taking precautions such as wearing comfortable clothing and avoiding tight-fitting jewellery may affect lymph drainage.

Will having manicures or using a hot-tub affect my risk?
There is no evidence that having manicures or using hot tubs increases your risk of lymphoedema.

Will massage affect my risk?
Deep tissue massage will encourage more fluid to the treated area so you may want to avoid this on your ‘at risk’ side. However, many therapists are now trained to work with people who have, or are at risk of, lymphoedema, so check with your therapist. You can find out more about massage in our Complementary therapies, relaxation and wellbeing booklet.

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

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

Contact your GP or breast care nurse as soon as possible if you have:

- redness or a rash
- heat
- swelling
- tenderness or pain
- flu-like symptoms

You may need antibiotic treatment.
Injections, blood tests, blood pressure readings and intravenous fluids

There’s no strong evidence that having injections, taking blood, taking a blood pressure reading or having intravenous fluids in your ‘at risk’ arm will cause lymphoedema. However, you may prefer to use your other arm.

Speak to your healthcare professional if you’re worried about having any of these procedures on your affected side.

Travel

When travelling you may want to consider the following.

During flights or long train and car journeys, do gentle exercises such as clenching and unclenching your fist and shrugging your shoulders to reduce the risk of swelling.

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’re 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, even if there’s no swelling.

There’s 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 problems.
What should I do if I notice swelling?

Contact your breast care nurse or treatment team as soon as possible if you notice:

- swelling in your arm, hand, fingers, breast or chest area
- pain or discomfort
- reddening of the skin

They can assess your symptoms and may investigate further to rule out other causes for the swelling.

Most people with lymphoedema have mild to moderate 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, if it’s severe 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 breast care nurse or treatment team, talk to your GP and ask to be referred 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 treating and managing lymphoedema, see our booklet *Living with lymphoedema after breast cancer*.
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 the Breast Cancer Care Helpline on 0808 800 6000 or visit our website breastcancercare.org.uk

Useful organisations

British Lymphology Society (BLS)
thebls.com
Website includes a directory of lymphoedema clinics around the country.

The Lymphoedema Support Network
lymphoedema.org
020 7351 4480
Provides information and support to people with lymphoedema.
Four ways to get support

We hope this information was helpful, but if you have questions, want to talk to someone or read more about breast cancer, here’s how you can.

Speak to our nurses or trained experts. Call our free Helpline on 0808 800 6000 (Monday to Friday 9am–4pm and Saturday 9am–1pm). The Helpline can also put you in touch with someone who knows what it’s like to have breast cancer.

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
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.

Donate today and together we can ensure that everyone affected by breast cancer has someone to turn to.

**Donate online**
Donate using your debit or credit card breastcancercare.org.uk/donate

**Donate by post**
Please accept my donation of **£10/£20/my own choice of £**

I enclose a cheque/PO/CAF voucher made payable to Breast Cancer Care

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In addition, we’d love to keep you updated about our work and provide you with other opportunities to get involved with Breast Cancer Care. Please tell us how you would like to hear from us (by ticking these boxes you confirm you are 18 or over)

☐ I’d like to hear from you by email
☐ I’d like to hear from you by text message or SMS
☐ Please do not contact me by post
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We never give your information to other organisations to use for their own purposes. To change your preferences, or find out more information on how we use your data, please view our privacy policy at breastcancercare.org.uk or contact supporter services on 0345 092 0800.

Please return this form to Breast Cancer Care, Freepost RRKZ-ARZY-YCKG, Chester House, 1–3 Brixton Road, London SW9 6DE

Breast Cancer Care is a working name of Breast Cancer Care and Breast Cancer Now, a charity registered in England and Wales (1160558) and Scotland (SC045584).
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:

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Breast Cancer Care and Breast Cancer Now are uniting to create one charity for everyone affected by breast cancer. Our aim is that by 2050, everyone who develops breast cancer will live and be supported to live well.

From research to care, our new charity will have people affected by breast cancer at its heart – providing support for today and hope for the future. We’ll find ways to prevent the disease, improve early diagnosis, develop new treatments, campaign for better care, and support people with the physical and emotional impact of breast cancer.

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

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