

MANAGING LYMPHOEDEMA AFTER BREAST CANCER

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About this booklet

It's normal to have questions about lymphoedema. You may have developed lymphoedema recently, or you may have had it for a while.

This booklet guides you through what it can feel like and how to manage lymphoedema, and will hopefully answer any questions you have.

What is lymphoedema?

Lymphoedema is swelling caused by a build-up of fluid in the body's tissues. It usually affects the arm, but it may also affect the hand and fingers.

Lymphoedema can also affect the breast, chest, and occasionally the shoulder or the area on the back behind the armpit.

Lymphoedema is a long-term condition. This means it can be controlled after it has developed but it is unlikely to ever go away completely.

What causes lymphoedema?

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

This is because lymph nodes and vessels that are damaged or removed during surgery or radiotherapy cannot be replaced. This can affect the lymphatic system's ability to drain fluid in the affected area, so lymph fluid can build up in the surrounding tissues.

You may notice lymphoedema in the months after surgery, radiotherapy or sometimes chemotherapy. However, it can also occur many years later.

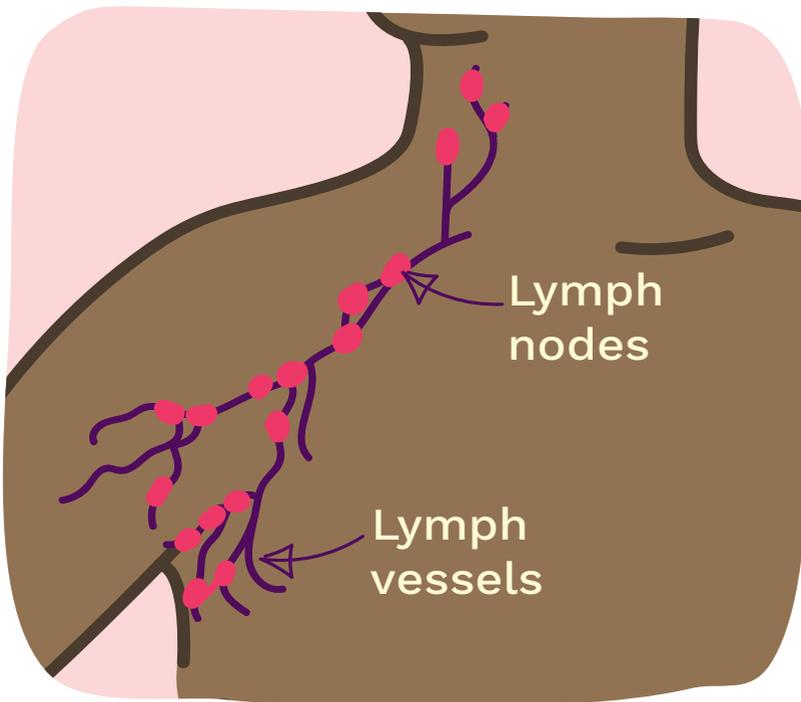
It can also be triggered by a skin infection called cellulitis or injury to the area.

In rare cases it can be caused by cancer cells blocking the lymphatic system.

The lymphatic system

The body's drainage and filtering system is called the lymphatic system. It's made up of lymph nodes (also called lymph glands), vessels and fluids. The vessels transport a fluid called lymph to the lymph nodes. It helps get rid of waste products and is part of our immune system.

Lymph nodes can also filter out cancer cells that have spread from a breast cancer.



The lymph nodes and vessels

I wasn't warned that lymphoedema could happen at any time so was really surprised when it developed 12 months after surgery.

Kim

Symptoms of lymphoedema

Lymphoedema symptoms can vary. It's important to get advice from your breast care nurse or treatment team as soon as you notice any of the following symptoms in your "at risk" side (this could be the arm, hand, fingers, breast, chest wall or shoulder of the side you had your treatment):

- Swelling
- Tightness
- Discomfort
- Dry skin
- Arm stiffness or heaviness
- Hardness or firmness (fibrosis)
- Pins and needles

For more information about lymphoedema symptoms, see our booklet **Reducing the risk of lymphoedema**.

Infection

If you have lymphoedema you are at risk of developing a type of skin infection called cellulitis.

You may have developed cellulitis if your arm, breast or chest area suddenly becomes:

- Red in colour (a rash)
- Tender or painful
- Hot
- Swollen

You may also have flu-like symptoms, which can be the first sign of an infection.

See your GP, treatment team or lymphoedema specialist urgently if you have these symptoms. You'll probably need to start taking antibiotics straight away. It's important to take the antibiotics for as long as your doctor has told you to.

If you have repeated infections, your doctor may prescribe you a low dose antibiotic to take continuously.

If you're travelling away from home, particularly if you're going abroad, you should take a supply of antibiotics with you in case you develop an infection while you're away. This is particularly important if you've had an infection in the past. Before you travel, talk this through with your GP, treatment team or lymphoedema specialist who will need to prescribe the antibiotics.

The Lymphoedema Support Network (lymphoedema.org) has guidelines on how to manage cellulitis in lymphoedema.

Managing lymphoedema

Where can I go for support?

Most people with lymphoedema have mild to moderate symptoms.

You may need to be referred to a specialist lymphoedema service for advice and treatment. They will assess your swelling and discuss the best way to manage your symptoms. You may need regular guidance from your lymphoedema specialist to help manage your lymphoedema at first.

Your breast care nurse, treatment team or GP can refer you to a specialist lymphoedema service.

The sooner you're assessed and treated for lymphoedema, the easier it is to control.

The lymphoedema organisations listed at the end of the booklet can also provide information and support.

How is lymphoedema managed?

There are various treatments and techniques to manage lymphoedema. These aim to:

- Encourage lymph fluid to move away from the swollen area
- Improve symptoms of lymphoedema
- Stop symptoms getting worse

Managing lymphoedema may involve some, or all, of the following:

- Skincare
- Physical activity and exercise
- Compression garments
- Compression bandages
- Maintaining a healthy weight
- Manual lymphatic drainage (MLD)
- Self lymphatic drainage (SLD)
- Kinesio Taping (an adhesive tape that helps encourage lymphatic drainage)
- Surgery

You may be able to manage some of these yourself, such as skincare, physical activity and exercise, under the guidance of your GP or treatment team. However, you may also have specialist treatment to help manage your lymphoedema.



Skincare

Having excess lymph fluid in areas with fewer lymph nodes can increase the risk of infection in these areas.

An infection can damage the lymphatic system and may make lymphoedema worse.

Having a good skincare routine can help reduce the risk of infection. Here are some tips to help you keep your skin in the best possible condition.

Keep the area clean

Wash your skin with warm water every day and dry it thoroughly.

If your fingers are swollen, carefully wash and dry between them. This will help stop fungal infections that can develop in warm, moist areas.

Moisturise

Dry, flaky or cracked skin can lead to infection. Infections can worsen existing lymphoedema, or even trigger lymphoedema to develop. This can make it harder for you to control any swelling.

You can help avoid this by moisturising your “at risk” arm with moisturising cream every morning and evening.

Use gentle strokes to apply the cream towards your armpit. Always finish with the last stroke in the direction of the hair, ensuring that the hairs are laid down.

Wait at least 20 minutes after moisturising before putting a compression garment on.

I was told I could use whatever moisturiser I preferred, so although I usually use something relatively cheap, I do occasionally spoil myself with something that feels more luxurious! A little bit of luxury makes it seem less of a chore.

Mary

Avoid damage to the skin

Any break in the skin can become a site for infection. To avoid damaging your skin:

- Wear gloves when washing up, gardening or taking hot dishes out of the oven
- Use insect repellent containing at least 50% DEET to prevent bites or stings
- Take extra care if removing underarm hair or hair on your arm – an electric razor or hair removal cream are less likely to damage the skin (use hair removal cream with caution after patch testing)
- Take care when cutting your nails and avoid cutting your cuticles or pushing them back too harshly
- Keep hydrated, as dehydration can lead to dry skin, which can increase the risk of infection
- Ask your therapist to avoid the “at risk” areas if you have acupuncture

Treat any cuts, scratches and bites

Treat any cuts, scratches and insect or animal bites promptly by cleaning with warm water and applying an antiseptic cream or spray. This will reduce the risk of infection.

If it's a deep cut, use a dry dressing with a loosely applied bandage. You can also use a plaster if your skin is in good condition.

Take care in the sun and heat

Hot weather, and in some cases saunas, steam baths or hot tubs, can increase swelling.

Sunburn can damage the skin. You can still get sunburnt through some clothing and compression garments. To avoid getting burnt in the sun:

- Apply a high factor sunscreen (at least SPF30) regularly
- Protect the swollen areas of your body from the sun with loose cotton clothes with long sleeves

If you're feeling too hot, you can keep a spare garment in a plastic bag in the fridge so it's cold before you put it on.

I generally stay in the shade and cover my arm from direct sunlight.

Becca

I've heard of people putting their compression garments in the fridge on a hot day for a little while before they put them on to help with keeping cool!

Katie

Avoid tightness or strain

Any tightness around the swollen area can affect lymph drainage. If possible, avoid clothing or jewellery that is tight, such as narrow bra straps, tight sleeves, watches or rings.



Physical activity

Physical activity is a good way of managing swelling. This is because moving the muscles encourages lymph fluid to move away from the swollen area.

It's usually possible to carry on doing any exercise and sporting activities you did before you developed lymphoedema. However, you may not be able to perform at the same level as before.

If you want to increase your activity levels or take up a new activity, do it gradually. Stop if you have any discomfort or notice further swelling.

Some people find activities such as running, swimming, cycling, Nordic walking and yoga helpful.

If you use gym equipment, speak to your lymphoedema specialist or treatment team to make sure that it's safe to do so. Start with light weights until you've built up enough strength to use heavier ones without discomfort or increased swelling.

If you have a compression garment, wear this when exercising. If your compression garment is uncomfortable, make an appointment to get the size checked with whoever fitted the garment.

You don't need to wear compression garments while swimming. Wash your skin after swimming to get rid of chemicals from the pool or salt from the sea.

Deep breathing exercises can also help the movement of lymph fluid. You can find more information and tips by searching "Exercise, positioning and lymphoedema" on the Cancer Research UK website [cancerresearchuk.org](https://www.cancerresearchuk.org)

I like to keep fit and so regularly run and use a spinning bike which I think help to manage my lymphoedema. I use light arms weights regularly to ensure that I am using my arm frequently. I find these all help to keep my lymphoedema manageable.

Rosie

Arm and shoulder exercises

Your lymphoedema specialist, breast care nurse or physiotherapist may give you some specific shoulder, arm or hand exercises to encourage movement and help improve lymph drainage.

Keeping your arm and shoulder moving will help avoid stiffness and prevent further swelling.

You can find some simple arm and shoulder exercises on the opposite page.

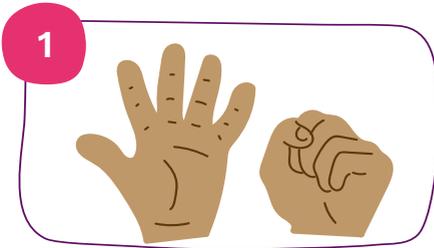
Get advice from your lymphoedema specialist if you can't do a movement fully or if the exercises cause you pain. Let them know about any pre-existing arm and shoulder problems so they can help you adapt the exercises.

You can exercise your arm when you're walking around by slowly bending and straightening it at the elbow. To relieve pressure and swelling in your hand, try slowly opening and closing your fist as if you're squeezing a rubber ball. Avoid letting your arm hang down for long periods of time, as this can encourage the lymph fluid to collect. Keep your arm at chest level when resting.

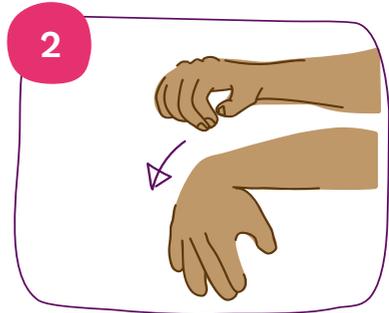
If you're unsure about what exercises to do, speak to your lymphoedema specialist, breast care nurse or physiotherapist.

How to do the exercises

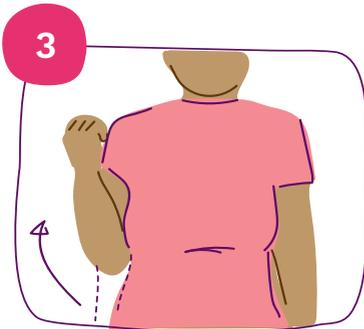
It's important to do the exercises in the order they are shown. You should do all exercises slowly and gently. This is because fast movements will not allow lymph fluid to drain properly. Try to do these exercises 3 or 4 times a day.



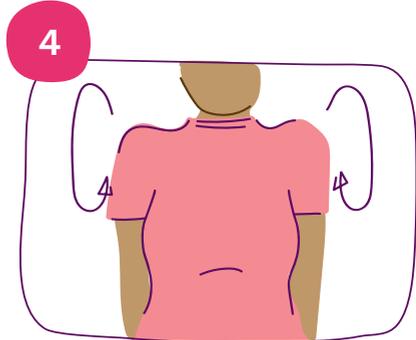
Open and close your hand



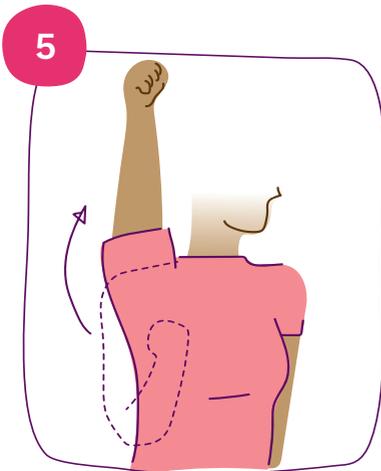
Move your wrist forward and back



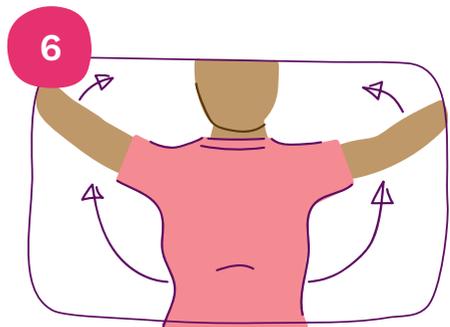
Bend and straighten your elbow



Roll your shoulders backwards



Raise your arm from your side up above your head and gently lower back down



Raise your arms up towards the ceiling and gently lower back down



Maintaining a healthy weight

It's important to try to maintain a healthy weight, as this can affect how much your arm swells and how you may respond to treatment.

Eating healthily and doing some regular physical activity can help you maintain a healthy body weight.

If you're concerned about your weight, your lymphoedema specialist, treatment team or GP may be able to advise you on losing weight. Or they may refer you to a dietitian for further advice and support.

The NHS website has information on losing weight. You can also see our booklet **Diet and breast cancer** for more information about healthy eating.

Compression garments

Compression garments are designed to encourage lymph fluid to drain away from the affected area. This helps to reduce existing swelling and prevent further swelling.

Your lymphoedema specialist will assess your symptoms to see which size and type of garment is most suited to your needs. This might be:

- A compression sleeve or glove (if the swelling is in your arm or hand)
- A compression bra or vest, similar to a sports bra (if the swelling is in your breast or chest area)

The compression garment may feel uncomfortable at first, but it should be supportive without causing pain or discomfort. If you have any concerns about the garment, contact the lymphoedema specialist who fitted it.

How to put your garment on

The lymphoedema specialist fitting the garment will show you how to put it on and take it off properly.

It's sometimes difficult to apply compression sleeves, so they should give you an applicator. The Lymphoedema Support Network (see page 32) can also tell you where you can buy applicators.

When using a compression garment:

- Put it on in the morning when there is usually less swelling
- Make sure it doesn't have any wrinkles and that the fabric is evenly spread
- Never turn the top of the garment over if it seems too long, as this will put too much pressure on one area (you may need a shorter garment instead, so talk to your lymphoedema specialist)

I saw the NHS lymphoedema nurses who prescribed a compression bandage for my arm (that initially incorporated my wrist and lower hand) and a very firm compression bra for when I'm exercising.

Kim

When to wear your garment

The compression garment is most useful when your muscles are working actively. It is least useful during rest.

You can start by wearing it for a few hours each day, then gradually increase the time so you're eventually wearing it all day. Your lymphoedema specialist will advise you about this.

If you're struggling with wearing a garment, and your lymphoedema specialist has checked it fits correctly, try wearing it when you're at your most active. This could be when you're doing exercise, gardening, housework or physical work. You can then take it off when you're less active.

Your lymphoedema specialist may suggest wearing your compression garments when flying. This may be more beneficial for long-haul flights (over 4 hours). Regular exercise and self-massage may also help manage any swelling.

Wear your compression bra, if you have been given 1, during daytime hours. Your lymphoedema specialist will tell you if it's suitable to wear it at night if you find it comfortable to do so.

Some compression sleeves are also designed to be worn at night. You can ask your lymphoedema specialist if this would be appropriate for you.

Problems to look out for

Size and fit

If you have concerns about the fit of your compression garment, speak to your lymphoedema specialist.

Pain, numbness or tingling

Take your compression garment off immediately and contact your lymphoedema specialist if you notice:

- Pain when you wear your garment
- A change in sensation in your arm or hand, such as numbness or tingling
- A change in colour at the tips of your fingers
- A skin reaction when wearing the garment

The garment may be too tight.

Soreness or itchiness

Sometimes the material of the garment can make your skin sore or itchy, particularly in the elbow crease or over bony areas on your hand. However, these symptoms may also mean you're allergic to the material.

Talk to your lymphoedema specialist or GP to see if you can try other garments.

It is a good idea to keep moisturised, as dry skin gets itchy and puts you more at risk of getting little cuts which in turn can cause infection.

Julie

Coverage

You may need to try a different garment if you notice swelling in areas the current garment doesn't cover.

Infection (cellulitis)

If you have an infection, your arm, hand, breast or chest may feel uncomfortable. However, it's important to keep wearing the garment.

See page 5 for more information on infection, including the signs to look out for and who to report them to.

Replacing your garment

You'll normally be given 2 compression garments. This is so you can wash 1 while wearing the other. Regular washing according to the care instructions will make the compression garment last longer.

You'll need to replace the compression garments about every 6 months to make sure the compression level remains correct for the amount of swelling you have.

Contact your lymphoedema specialist about getting a replacement garment.



Compression bandages

Sometimes the swelling makes it difficult for a compression garment to fit your arm correctly. If this is the case, your lymphoedema specialist may talk to you about compression bandages.

Compression bandages can also be used if your skin has become damaged and sore. This is because compression garments may cause more damage in these instances.

Your lymphoedema specialist, or another trained healthcare professional, will put several layers of bandages on your arm. At first these can make your arm seem bigger than normal. They may also feel bulky, so you may need to wear clothes that allow for the extra bulk of the bandages.

You'll need to go to the lymphoedema clinic regularly to have the bandages changed.

Usually your arm shape will change and the swelling reduce over 2 to 4 weeks of regular bandaging. Once the swelling has reduced your lymphoedema specialist will then be able to fit compression garments to control any swelling that remains.

It's important to exercise and move your arm as much as possible while the bandages are in place. This will improve their effectiveness.

An alternative to compression bandages for your arm and hand are compression wraps. These are foam tubes with Velcro fastenings. Your lymphoedema specialist will let you know if these are suitable for you.

Can I still go on holiday?

There's no reason why lymphoedema should stop you enjoying holidays.

Before you travel, talk to your GP or lymphoedema specialist about taking a course of antibiotics with you in case you develop an infection while you're away.

Try not to sit for too long in the same position when travelling. Take regular breaks if travelling by car or move around if you're travelling by air. You can also do gentle exercises while sitting to help lymph flow. If you've been fitted with a compression garment, wear it while travelling.

It's important to avoid getting sunburnt (see page 10).



Manual lymphatic drainage (MLD)

Manual lymphatic drainage (MLD) is a specialised type of massage carried out by a trained practitioner. It can be used for any swelling caused by lymphoedema, but it's usually used when the swelling is severe or difficult to manage. MLD can be particularly useful over areas where compression garments can't easily be worn, such as the breast or chest.

The MLD therapist uses hand movements to stimulate lymph drainage and move lymph fluid away from areas where it has collected. It's a slow, rhythmical treatment that takes time to complete.

MLD is usually combined with other compression treatments, such as a compression garment, to achieve a better result. MLD can help to reduce hardness of the tissues (fibrosis), as well as reduce pain and discomfort.

Your lymphoedema specialist can discuss if MLD may be helpful for you. This treatment is available in some NHS hospitals, Macmillan centres or privately. To find out if there is a trained MLD therapist in your area, talk to your lymphoedema specialist or contact one of the organisations on page 32.

If you use a private MLD therapist, check they're registered with MLD UK.

I was very lucky to find a lymphoedema nurse near to me. I was referred on the NHS for 15 sessions of MLD. This worked so well that I now see the same nurse as a private patient every 6 to 8 weeks.

Steph

Self lymphatic drainage (SLD)

Your lymphoedema specialist may teach you a simple type of skin massage called self lymphatic drainage (SLD). This is based on the principles of MLD.

If you've been taught SLD, your lymphoedema specialist will advise you to do it 1 or more times a day, depending on your condition. You need to do SLD carefully and not change the sequence of the movements you were taught.

If you find it difficult to do SLD yourself, someone else can be taught how to help you with it.

The technique is best done without using oils or cream on the skin, to keep good contact between the hand and the skin.

I have a self lymphatic drainage massage routine I do every day before I get up. It takes about 10 minutes and I believe that this routine, along with wearing my compression sleeve, has kept my lymphoedema manageable.

Lesley

A video demonstrating SLD is available on the Lymphoedema Support Network's YouTube channel.

Kinesio Taping

Kinesio Taping is suitable for some people with lymphoedema. It uses a particular type of adhesive tape that a lymphoedema specialist applies to the skin. They can show you how to replace the tape.

The tape lifts the skin during movement and encourages lymph fluid to move towards other areas and the lymph nodes.

Kinesio Tape is usually used with other forms of lymphoedema treatment. However, it's sometimes used on its own to manage lymphoedema if it develops in areas such as the breast and chest wall. It can also be used to soften and reduce fibrosis.

My therapist taught me Kinesio Taping methods and sometimes I use Kinesio Tape overnight or during the day under my glove, especially in summer when lymphoedema is often worse due to the heat.

Katie

Other treatments for lymphoedema

The following treatments are sometimes used to manage lymphoedema, but their benefits are less clear.

Surgery

Research is looking at using surgery to treat lymphoedema. Surgery may be considered for some people. However, it's not yet widely available and may not always be successful.

Lymphatic reconstruction

(lymphaticovenous anastomosis (LVA))

Microsurgery (lymphatic reconstruction) for lymphoedema is a relatively new procedure. It's done under local anaesthetic by plastic surgeons with special training in microsurgery. It aims to join lymph and blood vessels to help the lymphatic system transport more lymph fluid.

Lymph node transfer

Lymph node transfer involves removing healthy lymph nodes from 1 part of the body and transferring them to the armpit area.

Liposuction

This is a surgical procedure where fat is removed from the affected area.

It's not standard treatment for lymphoedema in the UK. It should not be considered before other therapies, such as exercise, compression bandaging and MLD, have been tried.

Liposuction aims to reduce swelling, improve movement and reduce pain and discomfort. People who have this procedure are advised to wear a life-long compression garment 24 hours a day to keep the swelling down.

Compression pumps

Mechanical compression pumps mimic the effect of MLD by squeezing the swollen arm in a plastic sleeve which inflates and deflates at regular intervals. Pumps are usually used alongside other lymphoedema treatments.

They should never be used without the advice and close supervision of your lymphoedema specialist.

Low-level laser therapy

Research is looking at using low-energy laser to improve the flow of lymph fluid. Some studies suggest it may be helpful in reducing the amount of swelling, fibrosis and discomfort.



Living with lymphoedema

For some people, living with lymphoedema can be harder than coming to terms with a diagnosis of breast cancer. You may have a mixture of feelings depending on the degree of swelling and how it affects your daily life.

Having lymphoedema can affect your self-confidence and body image, including how you feel about intimacy and sex. Reading our booklet **Your body, intimacy and sex** may be helpful.

You don't have to live with lymphoedema alone. Speak to your lymphoedema specialist, breast care nurse, treatment team or GP if you need help and support. You can also call our helpline on **0808 800 6000**.

You may find it helpful to talk to other people who are living with lymphoedema. We can put you in touch with a trained volunteer who has lymphoedema through our Someone Like Me service, so you can share experiences and get practical and emotional support. Call our Someone Like Me service on **0800 138 6551**.

The forum on our website has a specific section for people affected by lymphoedema, where you can chat to other people and share tips. You can find this at breastcancer.org/forum

It is really hard to think that you have had cancer and then to be told you have a life-long condition that's disfiguring. I found it took time to get used to wearing the sleeve in public. It gets easier with time.

Andrea

Sometimes I think people are looking at me on the street and then I remember perhaps it's the sleeve they're looking at, but honestly over time it doesn't bother me at all.

Katie

Useful organisations

British Lymphology Society (BLS)

thebls.com

Provides factsheets and a website that includes a directory of lymphoedema clinics around the country.

Lymphoedema Support Network

lymphoedema.org

020 7351 4480

The leading UK charity for people living with lymphoedema, providing information and support.

MLD UK

mlduk.org.uk

MLD UK is an organisation that can help you to find a manual lymph drainage (MLD) therapist in your area.

We're Breast Cancer Now, the research and support charity. However you're experiencing breast cancer, we're here.

Life-changing support

Whoever you are, and whatever your experience of breast cancer, our free services are here. Whether you're worried about breast cancer, dealing with a diagnosis, working out life with or beyond treatment – or someone you love is.

World-class research

We support over 290 of the brightest minds in breast cancer research. They're discovering how to prevent breast cancer, live well with the disease, and save lives. Every day, they get closer to the next breakthrough.

Change-making campaigns

We fight for the best possible treatment, services and care for everyone affected by breast cancer, alongside thousands of dedicated campaigners.

Could you help?

We don't get any government or NHS funding for our support services or health information. So, we rely on donations and gifts in wills to make our vital work happen. If you'd like to support us, go to breastcancer.org/give

ABOUT THIS BOOKLET

Managing lymphoedema after breast cancer was written by Breast Cancer Now'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:
Email health-info@breastcancer.org



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We're here

Information you can trust, support you can count on

Whatever breast cancer brings, we're here for you.

Whether you're looking for information about breast cancer or want to speak to someone who understands, you can rely on us.

Call **0808 800 6000** to talk things through with our helpline nurses.

Visit **breastcancer.org** for reliable breast cancer information.

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Patient Information Forum

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