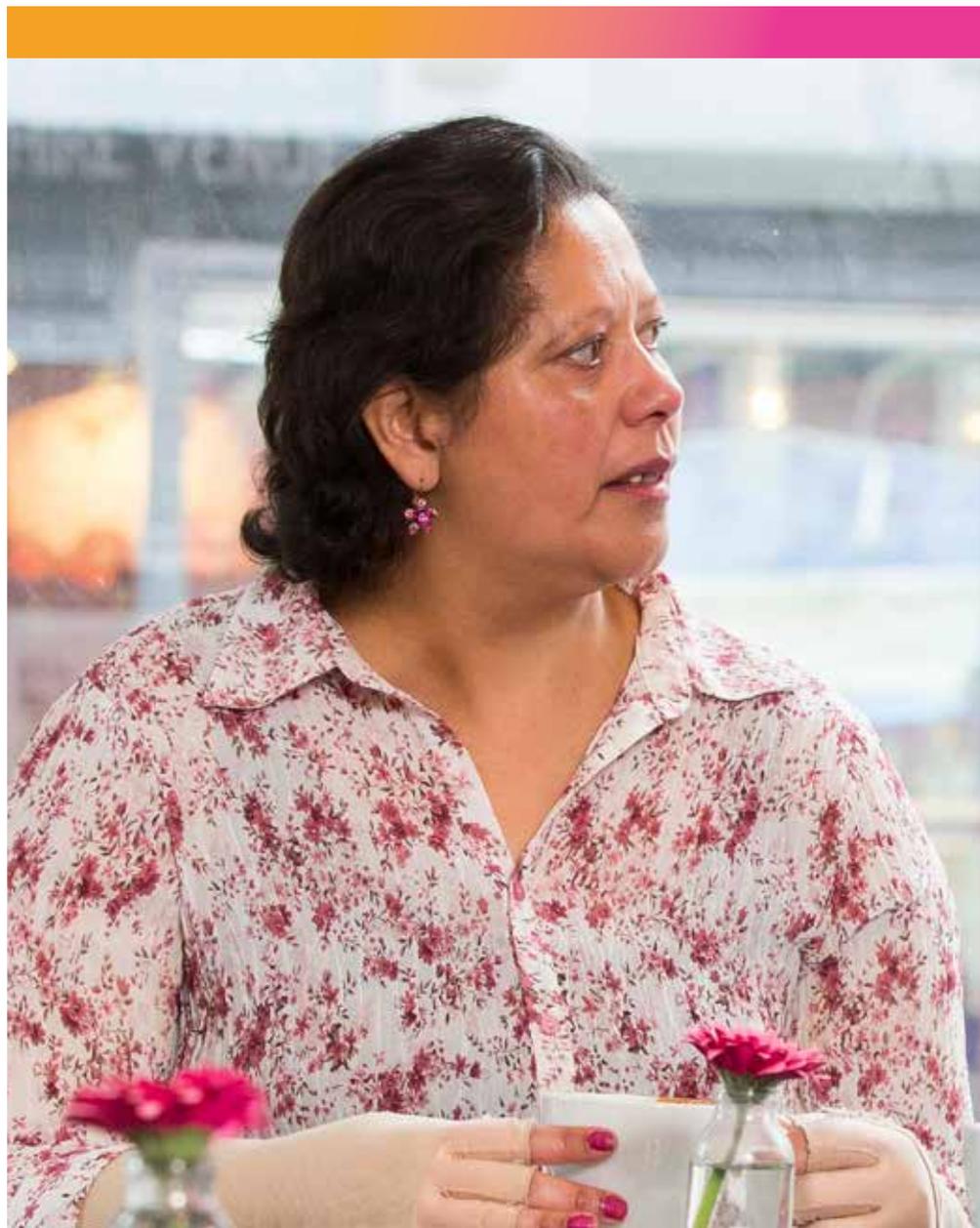


Living with lymphoedema after breast cancer

breast
cancer
care



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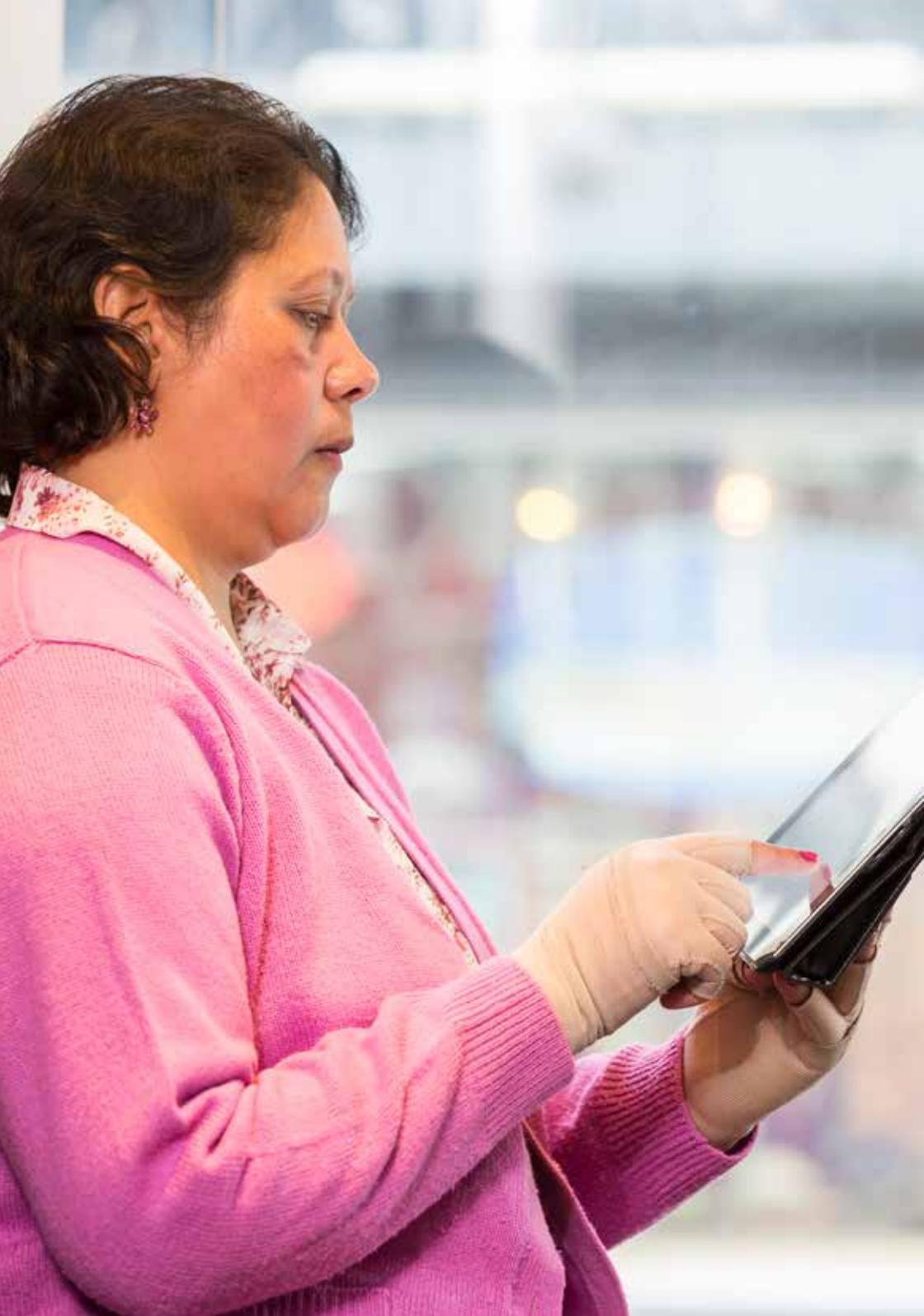
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Introduction

If you have recently developed lymphoedema, or have an ongoing problem with lymphoedema, this booklet will give you a general overview of the condition, how it may affect your life and how it can be managed.

For information about the risks of developing lymphoedema and for advice about reducing the risk, see our booklet **Reducing the risk of lymphoedema**.

'I first noticed that my right breast was larger than the other about three months after I finished radiotherapy. I went for a bra fitting and the difference in size was really noticeable. I initially thought that it was still swollen from radiotherapy but then I attended a Breast Cancer Care Moving Forward session on lymphoedema and the symptoms of breast lymphoedema were described. I asked the breast care nurse what she thought and she had a look and said it was definitely lymphoedema.'

Ruth

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 are often 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.

'My breast cancer was a low grade and stage and my surgery relatively minor, so finding out I had lymphoedema was a real shock. It shows how random lymphoedema can be. I'm more accepting of it now than I was initially. It's just part of the post-cancer me. But it still makes me feel rubbish about myself quite often. I do worry about it moving to my arm, so am very careful about skincare etc.'

Ruth

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. Occasionally, 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.

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

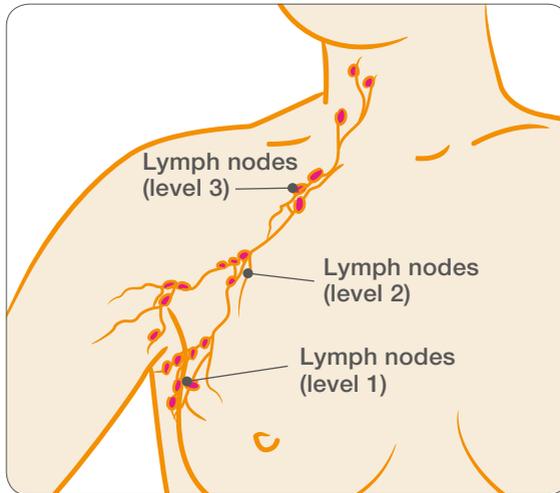
Kim

What is the lymphatic system?

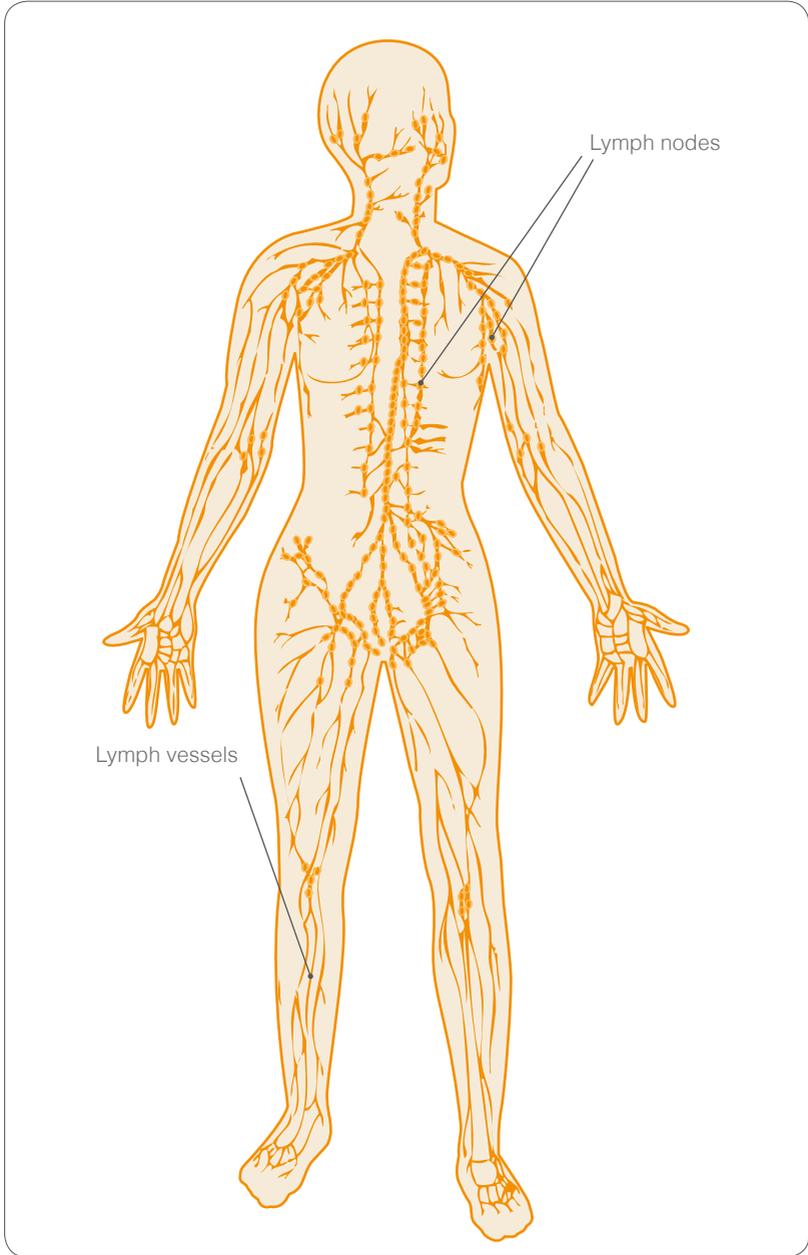
The drainage and filtering system of the body is made up of lymph nodes (also called lymph glands), vessels and fluid. It helps to get rid of waste products and fight infection.

The lymphatic vessels transport a straw-coloured fluid called lymph, which flows very 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 physical symptoms might I experience?

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. If swelling to your hand, arm, breast or chest develops later on, or after your cancer treatment is completed, you should get advice from your breast care nurse or a member of your specialist team as soon as possible. If you're assessed as having lymphoedema, you may remain under the care of your breast care nurse or be referred to a specialist lymphoedema service.

Swelling in the breast or chest wall following treatment for breast cancer can be uncomfortable and sometimes painful. A well-fitting bra with wide shoulder straps and deep sides can help to support the breast and ease some of the discomfort. A sports bra or compression vest can be useful. If you develop swelling in the breast, ask to be referred to a specialist lymphoedema therapist.

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. For more information see the 'Arm stiffness' section opposite.

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 infection and can lead to cellulitis (a sudden infection of the skin). Cellulitis causes the area of affected skin to become red, swollen and hot, and may cause pain or tenderness. You may also develop a temperature or fever. It is normally caused by a bacterial infection and you will need to have antibiotics. Keeping the skin supple and well moisturised is important, and you should moisturise your arm with an unperfumed moisturising cream at the beginning and end of every day. This is particularly important after a shower or bath.

If you wear a compression garment (see page 21), it's best not to apply moisturiser immediately before putting it on, as this can make it more difficult to put on and may damage the garment.

Arm stiffness

If your arm is swollen, it may limit movement in the joints. Exercise your arm and shoulder regularly in order to reduce stiffness and encourage lymph drainage. If you were given specific exercises after your surgery or radiotherapy it's vital to continue doing them for as long as recommended (see our leaflet **Exercises after breast cancer surgery** for more information). Try to keep up your normal level of activity as much as possible, but avoid movements that strain your arm or keep it in the same position for a period of time. See the 'Exercise' section on page 17 for more detail. You can also ask your specialist team or GP to refer you for physiotherapy.

Discomfort

Some people experience discomfort with lymphoedema. This may be a tight, heavy feeling in the arm or breast, and the discomfort tends to be dull and vague. Try doing some gentle exercise to relieve the discomfort. When you are sitting, rest your arm on a pillow or cushion at a comfortable level, but not above the height of your shoulder.

'I find having a small pillow at right angles under my affected elbow supports the arm and naturally allows the lymph fluid to drain back towards the shoulder area.'

Kim

Although lymphoedema isn't usually painful, pain relief (such as paracetamol) can sometimes help with any discomfort. If the discomfort continues or you experience sharp or sudden pain, speak to your breast care nurse, doctor or lymphoedema specialist who can look into the cause and advise on pain relief.

Infection

If your arm or chest area suddenly becomes red, tender and hot, with increased swelling or a rash, you may have developed an infection. You may also have flu-like symptoms which can be the first sign of an infection. These symptoms may mean you have cellulitis and you should see your GP (local doctor) urgently. You will probably need to start taking antibiotics straight away. Antibiotics for cellulitis in someone with lymphoedema should be taken for 14 days as prescribed, or until all signs of infection have cleared up.

For information on the type of antibiotics used to treat cellulitis in lymphoedema, see the 'Cellulitis consensus document' available from the Lymphoedema Support Network (details at the back of this booklet).

'Until recently I worked with young children. I use a lot of disposable gloves to protect my skin from germs if I am helping children with personal care as I can't wash my gloves every time I touch something mucky.'

Alison

If you have repeated infections you may be prescribed a low-dose antibiotic to take continuously for some time. If you're travelling away from home, particularly if you are going abroad, it's recommended that you take a supply of antibiotics with you in case you develop an infection while you are away. This is particularly important if you've had an infection in the past. Talk this through with your GP or lymphoedema specialist who will need to prescribe the antibiotics.

The Lymphoedema Support Network has two factsheets on infection called 'What is cellulitis?' and 'Management of cellulitis in lymphoedema' – see 'Other organisations' at the back of this booklet.

Treating lymphoedema

Where can I go for treatment?

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 have other symptoms, you may need to be referred to a specialist lymphoedema service for advice and treatment.

The lymphoedema organisations listed at the end of the booklet will also be able to help.

What treatments are available?

Most people with lymphoedema have mild to moderate symptoms. However, for some people the lymphoedema can be more severe. Your breast care nurse or lymphoedema specialist will assess your swelling and discuss the best way to manage your symptoms.

The aims of treatment for lymphoedema are to encourage lymph fluid to move away from the swollen area, to try and improve the physical symptoms and to stop them getting worse. The way this is done will vary depending on how severe your lymphoedema is but your treatment may include some, or all, of the following approaches at different times. These treatments aim to control your lymphoedema.

- Skincare
- Movement and exercise
- Compression garments
- Compression bandages
- Manual lymphatic drainage
- Simple lymphatic drainage
- Kinesio taping (an adhesive tape that helps to encourage lymphatic drainage)
- Surgery

You can manage things like skincare and exercise yourself, under the guidance of your GP or the team managing your lymphoedema, and alongside any professional treatment you are having.

Skincare

Skincare is important because having excess lymph fluid in the arm or chest area, together with having fewer infection-fighting lymph nodes, increases the risk of infection. Small breaks in or damage to the skin, or some skin conditions which cause the skin to become red and sore, can become a site for infection. Dry, flaky or cracked skin can also lead to infection and make controlling any swelling more difficult.

If an infection develops it can lead to further damage to the lymphatic system due to scarring and may make the lymphoedema worse.

Here are some ways to keep your skin in the best possible condition.

- Wash your skin with warm water every day. If your fingers are swollen, carefully wash and dry between them to stop fungal infections which can develop in warm, moist areas.
- Moisturise your arm at the beginning and end of every day with an unperfumed moisturising cream. This will help to keep the skin supple and stop it becoming dry and cracked.
- Using gentle strokes, apply the cream in the most comfortable way for you. Always finish with the last stroke in the direction of the hair, ensuring that the hairs are laid down. This helps to reduce spots forming at the hair follicles.
- Treat any cuts, scratches or insect bites on the swollen area promptly by cleaning with warm water and applying an antiseptic cream or spray to reduce the risk of infection (see the section on 'Infection' on page 12 for more information). If it's a deep cut, use a dry dressing with a loosely applied bandage or a plaster if your skin's in good condition. If you notice a rash or redness in or near the area, with or without pain, or an insect bite that does not heal, contact your doctor as soon as possible. You may need a course of antibiotics.

'I stroke/massage my affected arm once a day. I was told I could use whatever moisturiser I preferred, and so although I usually use something relatively cheap I do occasionally spoil myself with something that feels more luxurious! I don't like having to do these things as a result of the breast cancer, and a little bit of luxury makes it seem less of a chore.'

Mary

Try to avoid situations/things that could lead to you developing an infection.

- Wear gloves when washing up and using harsh detergents, or when gardening or taking hot dishes out of the oven.
- Use insect repellent to avoid bites or stings.
- Treat any scratches or bites from pets or other animals promptly.
- Avoid blood samples from or injections into your affected arm. The risk of any medical procedure making the affected area worse is small but where possible should be avoided. If both your arms are affected, blood samples may be taken from your legs or feet. However, in an emergency situation it may be necessary to use your affected arm(s).
- If you have acupuncture, ask your therapist to avoid the affected areas.
- Take extra care if removing underarm hair (or hair on your arm) – an electric razor or depilatory cream are safest as they are less likely to damage the skin. If using a depilatory cream use with caution after patch testing.
- Take care when cutting your nails and avoid cutting your cuticles or pushing them back too harshly.
- Extreme changes in temperature (such as saunas, steam bath or hot tubs) can cause increased swelling. You should also try to avoid getting burnt in the sun. Apply a high factor sunscreen (at least SPF30) regularly.

Lymph drainage can be affected if there is any tightness around the swollen area. If possible avoid:

- tight or narrow bra straps and tight sleeves, watches or rings – these can stop the lymph fluid flowing away from the swollen area
- carrying a heavy bag on the shoulder of the affected side
- having blood pressure readings taken on the swollen arm. You can request a blood pressure reading be taken from your leg if both arms are affected or you can ask your medical team to use a manual (not automatic) blood pressure cuff.

Exercise

Research shows that exercise is a good way of managing the swelling because movement of the muscles encourages lymph fluid to move away from the swollen area. Although you may already use your arm actively in your everyday life or work and get plenty of exercise in this way, extra exercise may be helpful to reduce discomfort and tenderness and keep your joints supple.

If you've been fitted with a lymphoedema garment (see 'Compression garments' on page 21), always wear it when you are exercising or when you are very active. This will help you to get the best results from the exercise. If your compression garment is not comfortable, you should go back to whoever fitted it for you to get the fit checked.

'Swimming is very good and helps to clear my upper arm, which in turn drains my hand. Pilates – helps to strengthen chest and shoulder which in turn helps to prevent fluid retention in the upper arm and chest area.'

Fiona

'I was a scuba diver before my diagnosis, and about six months after treatment I began diving again. It's great to be doing something I used to do, a bit like things being back to normal. I am aware that I cannot do as much with my "lymphoedema-arm", but once I am underwater that doesn't matter! The water pressure is also good for lymphoedema.'

Mary

Any exercise you do should be done in a gentle and controlled way, and by gradually building up the amount and intensity of the exercise. If you are in any doubt, ask your lymphoedema specialist or breast care nurse for advice. If you have any pain or discomfort in your arm or shoulder with any movement or exercise tell your lymphoedema specialist, breast care nurse or a physiotherapist.

Deep breathing exercises can also help to improve the flow of lymph fluid through the veins and lymph vessels.

Arm and shoulder exercises

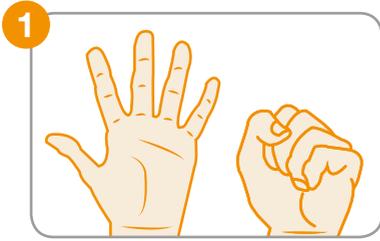
Keeping your arm and shoulder moving will help to avoid stiffness and prevent further swelling. Our leaflet **Exercises after breast cancer surgery** features arm and shoulder exercises for people who have had treatment for breast cancer. If you find you can't do a movement fully or the exercises cause you pain, it's best to get advice from your lymphoedema specialist or breast care nurse.

You can exercise your arm a little when you are walking around by slowly bending and straightening the elbow. To relieve pressure and swelling in the hand, try slowly opening and closing it as if squeezing a rubber ball. Try to avoid letting your arm hang down for long periods as this can encourage the lymph fluid to collect. Your lymphoedema specialist, breast care nurse or physiotherapist may give you some specific shoulder, arm and hand exercises to encourage movement and help improve lymph drainage. If you've been fitted with a compression garment it's advisable to wear this when doing these exercises, to get the best results.

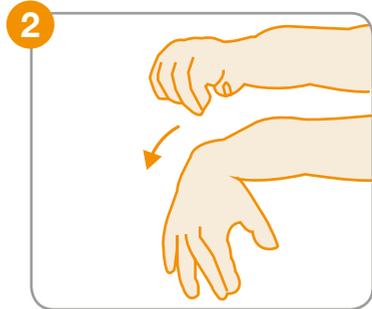
On the page opposite are some simple arm and shoulder exercises that you can try.

It is important to perform all exercises slowly and gently, in the order opposite. Fast movements will not allow lymph fluid to drain properly.

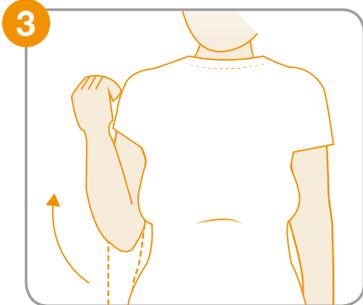
These exercises should be used as a guide. If you are unsure, ask your lymphoedema team, or ask to be referred to a physiotherapist.



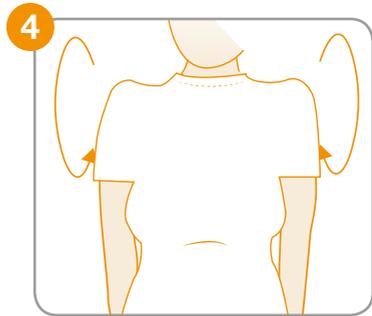
Open and close your hand



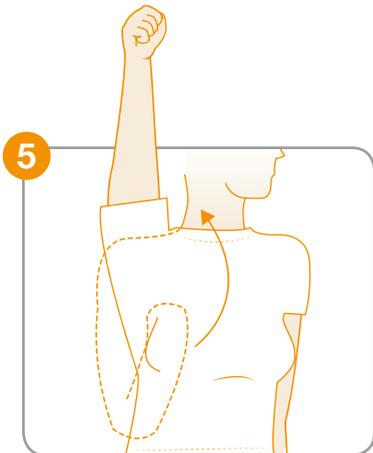
Move your wrist forward and back



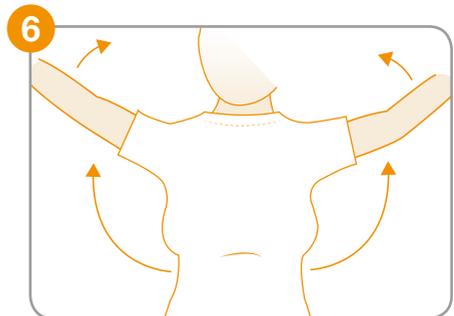
Bend and straighten your elbow



Roll your shoulders in a backward direction



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

Sport and fitness

Sports and activities that you did before you developed lymphoedema and those you wish to take up now are still possible, as long as you return to/start them slowly and stop if you have any discomfort or if you notice further swelling. Again, if you have been fitted with a compression garment always wear it when you are exercising, although it's not necessary to wear garments while swimming.

If you want to increase your activity levels or take up a new sport, make sure you do it gradually. If you use gym equipment, talk to an instructor and take care using heavy weights until you've built up enough strength to do so without discomfort or increased swelling. A number of women have got together and taken up activities such as running, cycling and dragon boat racing. Research suggests that exercise is helpful after breast cancer lymphoedema and does not make the lymphoedema worse. You should start with gentle exercises and gradually work up to more vigorous activity.

Maintaining a healthy weight

Being overweight can affect how much your arm swells and how you respond to treatment for lymphoedema, so it's important to try to keep your weight within normal limits. There's no specific diet that will help but if you are overweight, try to follow a healthy, well-balanced eating plan and a regular exercise programme. If you are concerned about your weight, your lymphoedema specialist or doctor may be able to advise you on how to get started, or they may refer you to a dietician.

General activities

Try not to use the affected arm for lengthy, strenuous activities such as lifting, carrying heavy shopping, or pushing heavy equipment like lawn mowers. If you can't avoid these activities, break up the time you spend on them by taking regular breaks.

'I avoid carrying heavy bags of any kind, or helping with chair or desk moving at work. I'm careful when working at the stables not to fill the wheelbarrow to full height before moving it – I prefer to do two journeys with lighter loads. I try to avoid using shoulder bags on the affected side, and take notice of any pressure that a rucksack may have on that arm also.'

Kim

Compression garments

If the swelling is in your arm and/or hand you may be fitted with a compression garment in the form of a sleeve and/or glove to help control your lymphoedema. If the swelling is in your breast or chest wall area, you may be prescribed a compression bra or vest. Your lymphoedema specialist or breast care nurse will assess which size and type of garment is best for you and this will usually be available on prescription.

Compression garments are designed to reduce existing swelling and prevent further swelling by encouraging lymph fluid to drain away from the affected arm. The garment provides a firm resistance against which the lymph vessels are squeezed by the muscles during activity.

Unless your specialist suggests otherwise, the garment is worn all day and taken off at night. Wearing the garment may feel quite strange at first but it shouldn't cause pain or discomfort and once on, it should feel comfortable and supportive. If you have any concerns about the garment, contact the person that supplied it. You'll normally be provided with two garments so that one can be washed while the other is being worn. Regular washing according to the care instructions will prolong the life of the garment but you will need replacement garments about every six months to ensure that the compression level remains correct for the amount of swelling you have.

Apply and remove your garment carefully. You may find that rubber gloves are helpful for easing it on. You might also find it helpful to hold onto a fixed support, such as a towel rail. This gives some resistance against which you can pull your garment up evenly. You may find it helpful to put your garment on by turning it two-thirds inside out to start with and pulling the first third on. Then pull the rest of the garment up a little at a time. This will make sure that the garment is applied correctly and that the compression is evenly spread along your arm to make it most effective. If you have difficulty putting your garment on or taking it off, speak to your lymphoedema specialist about using an applicator.

It is important that the garment does not have any wrinkles and that the fabric is even so that it fits well. 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 – again, talk to your lymphoedema specialist or breast care nurse.

Put your garment on in the morning when there is less swelling. If it feels too much to wear the garment all day, start by just wearing it for a few hours each day, gradually increasing the time so that you are eventually wearing it all day. If you find the garment difficult to cope with, and your lymphoedema specialist has checked that it fits correctly, try wearing it when you're at your most active – for example, when you are doing sports, gardening, housework or physical work – and then take it off when you are less active. Wearing your compression garment as much as you can during the day will help ensure your swelling is kept under control.

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

Evidence is limited to support the use of compression sleeves during air flight in people with lymphoedema. However, if you have been advised to wear a compression garment, many lymphoedema specialists suggest wearing it when flying. Long flights and a lot of time when you are not moving around can affect your swelling.

Contact your lymphoedema specialist or breast care nurse in the following situations.

- If you have concerns about the fit of your garment. If your weight changes, you may notice that your garment becomes too tight or too loose.
- If you find it painful to wear your garment, or you notice a change in sensation such as numbness or tingling in your arm/hand or possibly a change in colour at the tips of your fingers, take it off immediately and contact your lymphoedema specialist, as the garment may be too tight.
- 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. This could also mean you are allergic to the material. Talk to your lymphoedema specialist, breast care nurse or GP to see if you can try other garments.
- If you notice that swelling appears in areas not covered by the garment such as the fingers or hand, you may need a different garment.
- If you develop an infection in your arm or breast, your garment may be painful to wear. It's best to take off the garment until the infection has settled down and start wearing it again once your arm or breast feels less painful. If your skin has become sore as a result of the infection, wait until it has improved because the garment may damage the skin further. See page 12 for more information on infection.
- After wearing a compression garment for about six months, the fit and support will need to be checked and you should contact your lymphoedema specialist, breast care nurse or GP before getting your next new garment.

If you have swelling of the breast or chest wall you may be prescribed a compression bra (similar to a sports bra). This should be worn during daytime hours but may be worn at night as well if you find it more comfortable to do so.

Compression bandages

Compression bandages are used when the swelling has made the limb a difficult size or shape for compression garments to be fitted. They're also used if the skin has become damaged and sore as using compression garments at this time may cause further damage.

Several layers of bandages are put on the arm by a lymphoedema specialist or another healthcare professional who has received appropriate training. Initially these can make the arm seem bigger than normal and they may feel bulky and cumbersome. The bandages may be removed and reapplied regularly (depending on the severity). Over two to four weeks of regular bandaging the arm shape and size will change so that compression garments can be fitted to control the swelling that remains.

You will need to wear clothes that allow for the extra bulk of the bandages, and you will need to be able to go to the clinic on a regular basis to have the bandages changed. It's important to exercise and move your arm around as much as possible while the bandages are in place, as this will improve their effectiveness.

Your lymphoedema specialist will discuss the aims of compression bandaging with you if it's felt you would benefit from this type of treatment.

'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

Manual lymphatic drainage (MLD)

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

The MLD therapist uses specialised hand movements to stimulate lymph drainage and move lymph fluid away from areas where it has collected. It is a slow, very light rhythmical treatment that takes time to complete. MLD is not normally used as a treatment for lymphoedema on its own and is usually combined with other compression treatments to achieve a better result. MLD can help to reduce hardness of the tissues, as well as reduce pain and discomfort.

Your lymphoedema specialist will be able to tell you if MLD may help you. This treatment is available in some NHS hospitals, Macmillan centres or privately. To find out if there is a trained therapist in your area talk to your lymphoedema specialist or contact the Lymphoedema Support Network, British Lymphology Society or MLD UK (see the list of 'Other organisations' at the back of this booklet). If you decide to use a private therapist, check they are registered with the British Lymphology Society.

'While at a recuperation stay provided by my employers, I met another guest who asked if I'd heard of Vodder manual lymphatic drainage (MLD), which I had not. When I returned home I searched for a therapist and found one very local to me. Although it is a private treatment (not generally covered by the NHS), I was fortunate to be able to afford regular sessions with the therapist and after the very first massage, the difference was incredible!'

Kim

Simple lymphatic drainage (SLD)

Your lymphoedema specialist may teach you a simple type of skin massage based on the principles of MLD, which aims to improve lymph drainage in areas of the body near the swelling. The movements are not carried out on the swollen area but on areas of the body closest to this to make it easier for the lymph fluid to drain away. If you find it difficult to do the skin massage yourself, someone close to you can be taught how to help you with it.

If you have been taught SLD it should be carried out daily to stimulate the lymphatic system regularly. You need to do SLD carefully and not change the sequence of the movements because this will affect how well it works. The technique is best done without using oils or cream on the skin so that good contact is kept between the hand and the skin. The Lymphoedema Support Network has a self-help DVD which demonstrates SLD. See 'Other organisations' at the back of the booklet.

Kinesio taping

Kinesio taping is a treatment for lymphoedema that uses a particular type of adhesive tape applied to the skin by a trained therapist. You can be shown by your specialist 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 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 hard, firm tissue (fibrosis). The Lymphoedema Support Network has a factsheet 'The use of kinesio tape in lymphoedema management' – see 'Other organisations' at the back of this booklet.

Other treatments for lymphoedema

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

Surgery

Research is currently being carried out into the use of surgery to treat lymphoedema, and it may be considered for some people. However, it is not yet widely available and results are varied.

Lymphatic reconstruction

Microsurgery (lymphatic reconstruction) for lymphoedema is a relatively new procedure performed under local anaesthetic by plastic surgeons with special training in microsurgery. The aim is to make new routes by joining lymph and blood vessels, to help the lymphatic system transport more lymph fluid.

Lymph node transfer

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

Liposuction

This is a surgical procedure in which fat is removed from the affected area. It is not generally accepted as part of treatment for lymphoedema in the UK and is only considered in the most severe cases. It should not be considered before other therapies such as exercise, compression bandaging and MLD have been tried and achieved maximum benefit. The aim is to improve movement and reduce pain and discomfort. People who have this procedure are still advised to wear a life-long extra strong compression garment, 24 hours a day to maintain the loss of volume from the arm.

Compression pumps

There are some pumps specifically designed to treat lymphoedema alongside other treatments, but they should never be used without the advice and close supervision of your lymphoedema therapist. The newer, mechanical compression pumps mimic the effect of MLD by squeezing the swollen arm in a plastic sleeve that inflates and deflates at regular intervals.

Low-level laser therapy

This treatment uses a low-energy laser on the lymphatic channels to improve the flow of lymph fluid. Research into the use of this type of treatment is ongoing but some studies suggest it may be helpful for reducing the amount of swelling, fibrosis and pain.

What changes should I look out for?

Managing lymphoedema successfully means that initially you will need regular advice and guidance from your lymphoedema specialist. Your breast care nurse and GP can also help you manage your lymphoedema.

If you're concerned about your arm or chest area and/or breast at any time, you should contact your GP, lymphoedema specialist or breast care nurse, but particularly if you develop any of the following symptoms:

- painful arm, chest and/or breast with redness, or a rash, hot to the touch and which may be accompanied by flu-like symptoms (see 'Infection' on page 12)
- painful arm, chest and/or breast with possible increased swelling or other signs of problems with circulation, such as a noticeable change in colour or enlarged and visible veins
- increased swelling of the whole arm or isolated areas such as the fingers, chest or breast
- changes in feeling or ability to move your affected arm, hand or fingers.

Can I still go on holiday?

There's no reason why having lymphoedema should stop you enjoying holidays, but some extra care may be necessary.

- If you've been fitted with a compression garment, wear it during your journey.
- Wear loose, comfortable clothes when travelling to ensure that they are not too tight on your shoulder, arm and wrist.
- Use a suitcase on wheels rather than one you carry, and ask for help when moving luggage around. Keep your hand baggage light and try to carry it on your back rather than your shoulder.
- Try not to sit for too long in one position; take regular breaks if travelling by car or move around if you are travelling by air. Gentle exercises can also be done while sitting to promote lymph flow.
- A high factor sunscreen (SPF30+) applied regularly is essential to prevent sunburn if you're going somewhere hot. Loose cotton clothes with long sleeves will also help to protect your swollen areas from the sun.
- Use mosquito repellent every day, particularly in the evening and at night. Use a repellent containing at least 50% DEET as mosquito bites can become infected.
- If possible use cotton compression garments in hot weather as they tend to be more comfortable. Spray some water on your garment if you are feeling too hot. You can also keep a spare garment in a plastic bag in the fridge before putting it on to cool you down.
- Wash your skin after swimming in the sea or in a pool to get rid of the salt from the sea and chemicals from the pool.
- Before you travel, talk to your GP or lymphoedema specialist about taking antibiotics with you (in case you develop an infection in the swollen area).
- Try to avoid extremes of temperature – getting too hot then too cold, or too cold then too hot.

Managing lymphoedema

Managing lymphoedema may mean you have to make adjustments to your lifestyle, but a good understanding of the condition can help you to take control.

At first, you will probably need support from your lymphoedema specialist and other healthcare professionals, but over time many women are able to manage their symptoms as a part of their everyday life.

Self care is important, and involves being aware of the effects of lymphoedema and 'listening to your body'. For some people the swelling may restrict movement and make work, household jobs and daily activities such as dressing or washing difficult. Knowing what might make the swelling worse and either avoiding or changing these situations can help you control your lymphoedema. Exercising regularly and eating a healthy diet should also help you to manage your symptoms and improve wellbeing.

You may find that lymphoedema affects you on an emotional level as well as on a physical one. Some women find it difficult to get used to changes to their body, but find that once they've got into a good routine with things like skincare, wearing compression garments and SLD (simple lymphatic draining), they can move forward and feel more confident.

While most people are able to incorporate lymphoedema management into their daily life, if you think you need extra help, ask your lymphoedema specialist, breast care nurse or GP to refer you to an occupational therapist who will be able to assess your needs.

'It's disappointing, and a bit of a nuisance more than anything, and annoying when I'm tired. I have to be careful when travelling, especially with air travel and hot weather. But it's NOT the end of the world!'

Sue

Sometimes the swelling cannot be hidden away easily (particularly during the summer months) and may be a constant reminder of your breast cancer diagnosis. You may find that some people close to you find it hard to understand that a symptom like swelling can cause so much distress. It may be helpful for your family and friends to read this booklet to get a better understanding of what you're going through.

Managing your lymphoedema may mean that you need to make some adjustments to your lifestyle, but with appropriate treatment the symptoms can be reduced, helping to minimise the effect on your daily life.

'I see lymphoedema as being a nuisance, but have got used to wearing the sleeves and people asking what I've done to my arm (they usually think I have strained it). Sometimes I find it difficult to ask for help with, for example, heavy chair moving or placing a suitcase on the train from the platform or into the overhead rack, as the sleeve isn't noticeable if I have a coat on. I then feel I need to explain I have a problem with my arm – because as I am tall and look quite fit, people may think I'm taking the mickey!'

Kim

Coming to terms with lymphoedema

For some people, learning to live with and accept lymphoedema can be harder to come to terms with than the cancer itself. You may experience a mixture of feelings depending upon the degree of swelling and how it affects your daily life but it's normal to feel angry, resentful or fed up at times.

If there are times when you feel that you're not coping very well, don't be afraid to ask for help, either from your lymphoedema specialist or breast care nurse. You may find it helpful to talk to other people who are also living with the condition. We can put you in touch with a trained volunteer who has lymphoedema through our Someone Like Me service so that you can share experiences and get practical and emotional support.

For further information contact Breast Cancer Care's Helpline on **0808 800 6000** (Text Relay **18001**). The Forum on the Breast Cancer Care website has a specific section for people affected by lymphoedema where you can chat to other people and share tips.

Having lymphoedema can affect your self confidence because you may have to reconsider your favourite hobbies. Talk to your lymphoedema specialist about how you can modify your activities rather than stop them altogether. Lymphoedema can have an impact on your body image and self-esteem. This may affect you in a number of ways, including how you feel about intimacy and sex. Reading our booklet **Your body, intimacy and sex** may be helpful.

'I hate the flabby bits that stick out of the side of sleeveless tops. But I make myself get on with it and do it anyway. I can't let it bother me... I'm still here, that's the main thing.'

Sue





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

Lymphoedema organisations

British Lymphology Society (BLS)

24 Kiniths Crescent
West Bromwich
B71 4BX

Telephone: 01452 790 178

Email: info@thebls.com

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 Lymphoedema Support Network

St Luke's Crypt, Sydney Street
London SW3 6NH

Telephone: 020 7351 4480 (Information and support)

Telephone: 020 7351 0990 (Administration)

Fax: 020 7349 9809

Email: adminlsn@lymphoedema.freeserve.co.uk

Website: www.lymphoedema.org

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

The Lymphoedema Support Network has produced a lymphoedema alert bracelet which is helpful if you need to go into hospital for any reason. Wearing the bracelet during a stay in hospital helps alert doctors and nurses to your lymphoedema so they can avoid taking blood pressure readings and injections in the affected area.

MLD UK

PO Box 14491, Glenrothes
Fife KY6 3YE

Telephone/Fax: 0844 800 1988

Email: admin@mlduk.org.uk

Website: www.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 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.

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

Donate online

You can give using a debit or credit card at
www.breastcancercare.org.uk/donate

My details

Name _____

Address _____

_____ Postcode _____

Email address _____

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.

Please return this form to Breast Cancer Care, Freepost RRRKZ-ARZY-YCKG,
5-13 Great Suffolk Street, London SE1 0NS



About this booklet

Living with 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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Phone **0345 092 0808**

Email **publications@breastcancercare.org.uk**



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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