

Lymphoedema

J A S C A P

**JEET ASSOCIATION FOR SUPPORT TO CANCER PATIENTS, MUMBAI,
INDIA**

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JASCAP is a charitable trust that provides information on various aspects of cancer. This can help the patient and his family to understand the disease and its treatment and thus cope with it better.

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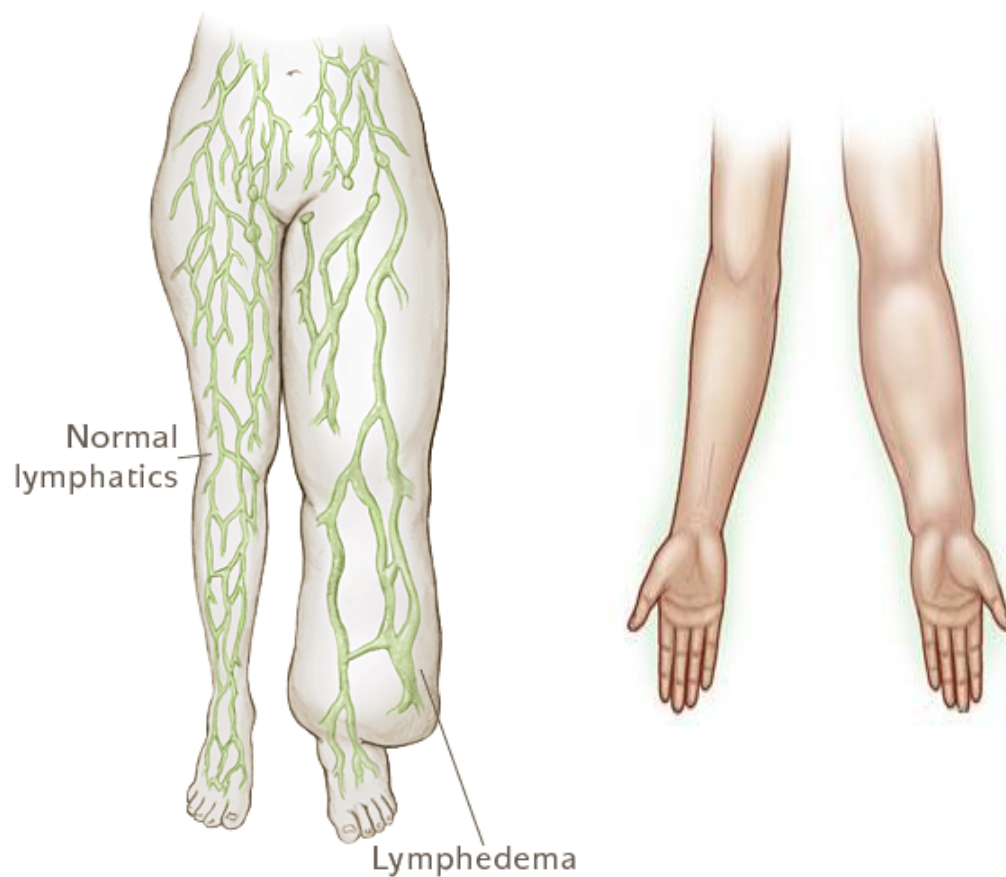
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Lymphoedema

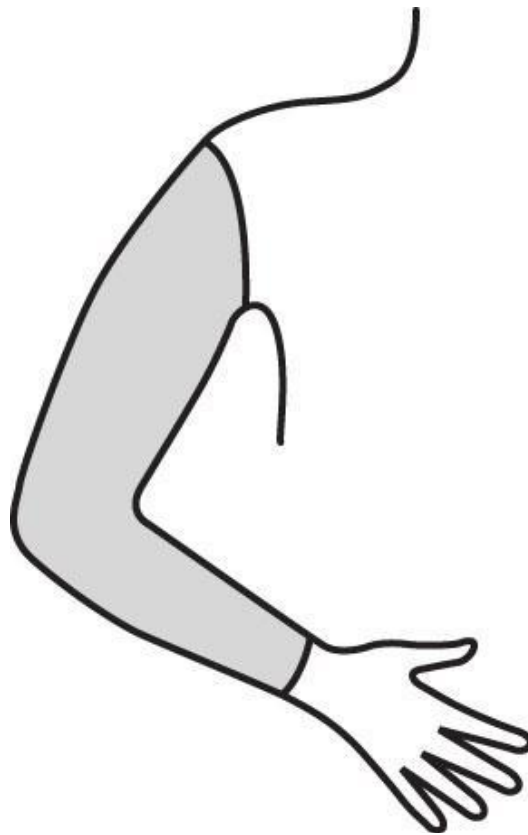
This booklet is for you if you have or someone close to you has lymphoedema – swelling, usually of the arm or leg – resulting from cancer or its treatment.

If you are a patient your doctor or nurse may wish to go through the booklet with you and mark sections that are particularly important for you.





Lymphodema pump



Lymphodema sleeve

Lymphoedema

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Lymphoedema

Introduction

This booklet gives information about lymphoedema (pronounced *limf-o-dee-ma*). Lymphoedema is the swelling of an arm, leg or other part of the body because of an abnormal collection of a fluid called lymph in the body tissues.

This booklet describes the treatment and gives tips on how to cope with the physical and emotional effects of lymphoedema.

About lymphoedema

Lymphoedema is the swelling of an arm, leg or other part of the body because of an abnormal build-up of a fluid called **lymph** in the body tissues.

This sometimes happens if cancer blocks the drainage of fluid through the lymphatic system.

It can also occur when part of the lymphatic drainage system has been removed by surgery or damaged by cancer treatments such as radiotherapy.

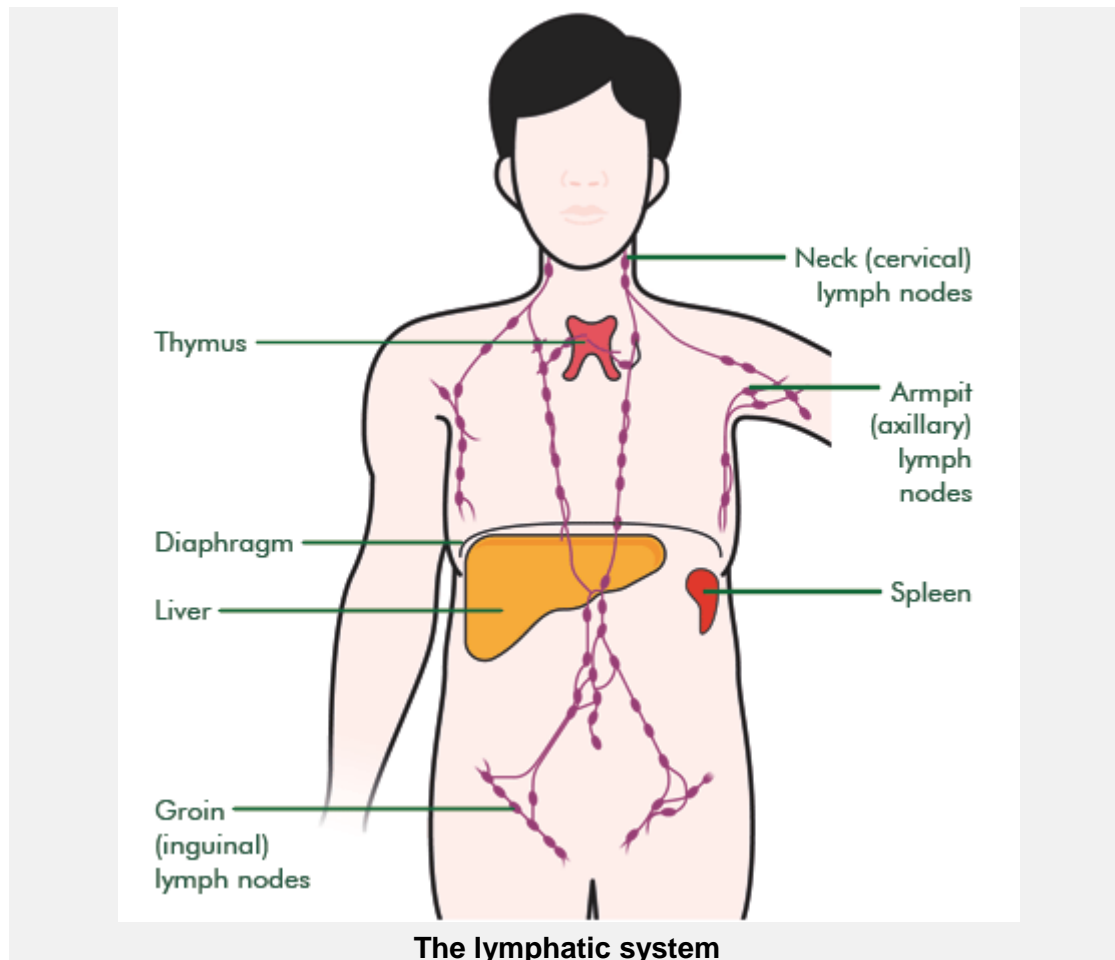
The lymphatic system

Its function

The lymphatic system:

- acts as a one-way drainage system to transport excess fluid from body tissues into the blood system
- contains cells which fight infection (*lymphocytes*)
- gets rid of waste products (chemicals) produced by cells.

The lymphatic system is made up of groups of lymph nodes throughout the body, connected by a network of lymphatic vessels. Lymph nodes are also called lymph glands.



Lymph vessels

The small lymph vessels join together to form larger lymph vessels, which pass through a number of lymph nodes. In the lymph nodes, bacteria and harmful substances are broken down. The fluid then travels through larger lymph ducts and drains into the bloodstream.

Lymph nodes

Lymph nodes are found throughout the body, but mainly in the neck, armpit, groin and abdomen. They are made of **lymphoid tissue**. This tissue contains special cells that can help to fight infection and other diseases such as cancer.

Lymph nodes vary in size: some are as small as a pinhead and others are about the size of a baked bean. The number of lymph nodes in the body varies from person to person. Different parts of the body also have different numbers of nodes: in the armpit, for example, there will be about 15-30 small nodes. At the back of the abdomen there are several large nodes.

As lymph flows through the lymph nodes, the nodes collect and filter out anything the body does not need or that could harm it. This includes bacteria, viruses, other infectious organisms, damaged cells or cancer cells.

Inside the lymph nodes, white blood cells (lymphocytes) attack and break down bacteria or other harmful cells. Waste products and the destroyed bacteria are then carried in the lymph into the bloodstream and are got rid of with other body waste.

Sometimes the lymph nodes trap bacteria or viruses that they cannot destroy immediately. The lymph node will then usually swell and become hot, painful and sore when touched. This can usually be treated with antibiotics.

Sometimes the lymph nodes will develop or trap cancer cells that they cannot destroy. The cancer cells may then continue to divide and produce new cells within the node. If this happens, the swollen nodes are often painless and are not uncomfortable when touched. Some cancers start in the lymphatic system, in which case they are called lymphomas. Sometimes the cancer cells may spread into the lymph glands from a cancer in another part of the body, such as the **breast** , **lung** or **bowel** .

It is important to check with your doctor if you have a painless, swollen lymph node, although the swelling is likely to be caused by something other than cancer.

Causes of lymphoedema

If a lymph vessel or node becomes blocked, the lymph fluid is unable to pass along it. Because the excess tissue fluid cannot drain away normally, it builds up and causes swelling. The medical name for swelling is **oedema** (pronounced *e-dee-ma*). When the swelling is due to a problem in the lymph system, it is called lymphoedema.

Lymphoedema is not always related to cancer.

Non-cancer related lymphoedema

Also called **primary lymphoedema**, this occurs because the lymphatic system has not formed properly, but this is rare. It can also be caused by other medical conditions that affect the lymphatic system.

Cancer-related lymphoedema

Also called **secondary lymphoedema**, this is caused by cancer or its treatment. It can occur if the lymph nodes are blocked with cancer or if they have been removed by **surgery**. **Radiotherapy** can also cause lymphoedema by causing a build-up of scar tissue within the lymph nodes.

Not everyone who has radiotherapy to the lymph nodes will get lymphoedema. Lymphoedema is more likely to occur if surgery and radiotherapy are both given together to the same area - for example, when lymph nodes are removed from the armpit during surgery for **breast cancer** and the area is then treated with radiotherapy.

Surgery or radiotherapy given on their own to a part of the body are less likely to result in lymphoedema.

Lymphoedema after cancer treatment

The most common areas for lymphoedema to occur after cancer treatment are:

- in the arm after breast cancer treatment to the armpit
- in the leg if cancer or its treatment affects nodes in the groin area or the pelvis.

The affected arm or leg may become swollen, stiff, uncomfortable and awkward to move, making it difficult to do daily activities, such as dressing or washing.

Lymphoedema can develop weeks, months or even years after cancer treatment and it is difficult to know who will be affected or how bad the lymphoedema will be.

Although lymphoedema is usually found in an arm or leg, other parts of the body can become swollen. There may be swelling of the chest or abdomen (trunk) or groin. Swelling of the breast or chest area can sometimes occur after breast-conserving surgery. If the lymph nodes in the neck are affected, the face may swell, but this is rare.

It is not possible to replace lymph nodes that have been removed or lymphatic vessels that have been damaged, but there are things that can help to prevent lymphoedema.

Once lymphoedema has developed it cannot be cured permanently. However, it can usually be reduced and controlled.

Effects of lymphoedema

Lymphoedema can affect you in different ways. Your doctor or nurse from the hospital team will know your medical history. They are the best people to tell you if a problem you have is caused by lymphoedema or some other condition.

Lymphoedema may cause the following symptoms in the affected area:

- a feeling of fullness or heaviness
- tightness and stretching of the skin
- swelling
- reduced movement of the joints
- thickening and dryness of the skin
- discomfort and/or pain.

You may first realise you have swelling because clothing, shoes or jewellery (such as rings or watches) feel tighter than usual.

Occasionally, in more severe lymphoedema, the skin may become broken and the colourless lymph fluid can leak out onto the surface. This is known as **lymphorrhoea** (pronounced *lim-for-ria*). This happens when too much fluid builds up in the tissues or when the skin is damaged. However, it is important to remember that most people with lymphoedema only have mild symptoms.

Preventing lymphoedema

You are at risk of developing lymphoedema if you have had radiotherapy to your groin or armpit, or if you have had surgery to remove lymph nodes.

You can help to prevent lymphoedema by trying not to put too much strain on your lymphatic system. This means trying to avoid infection or inflammation in the treated

area. So, you need to avoid cuts or grazes, insect bites and stings if at all possible. Following the tips on [skin care](#) should help you minimise your risk.

Gentle exercise can be helpful but it is sensible not to over-exercise the area as this may increase the risk of lymphoedema developing. Your nurse, lymphoedema specialist or a physiotherapist can advise you about exercise and there is more information on [exercises](#) later on this booklet.

Where to go for treatment for lymphoedema

If you notice any [symptoms](#) that may be lymphoedema you should contact either your GP, hospital doctors or, if you have had [breast cancer](#), your breast care nurse.

In some areas of the country there are specialist lymphoedema centres where treatment and advice are given. Your doctor or nurse should be able to tell you if there is a centre in your area.

Most lymphoedema services are provided free of charge so you shouldn't need to pay to see a therapist, unless you particularly want to.

Treatment for lymphoedema

The aim of treatment for lymphoedema is to relieve discomfort by reducing swelling and to prevent more build-up of fluid.

A lot can be done to manage lymphoedema, but it is a long-term problem. Although the swelling can usually be reduced, there is always a risk of it coming back. It may take several weeks or months before you notice any real improvement, but with treatment the affected part of the body should become less swollen, easier to move and less uncomfortable.

There are six different aspects of treatment:

- [Skin care](#) and preventing infection
- [Limb positioning and movement](#)
- Support using [compression garments](#) such as sleeves, stockings, special bras, or compression bandages
- [Exercises](#)
- A particular type of massage called [manual lymphatic drainage \(MLD\)](#)
- Self-massage

The therapies may need to be done every day to give the best results. You will be shown how to carry them out for yourself at home. Many people soon develop a routine that builds their lymphoedema care into their everyday activities.

Skin care and lymphoedema

Good skin care plays a vital part in the [treatment of lymphoedema](#). Lymphoedema can make the skin become dry and itchy and it may crack. Good moisturising can help to prevent this.

You can buy suitable creams from your local chemist or get them on prescription from your doctor. Your lymphoedema therapist can give you further advice on how to moisturise your skin.

Any break in the skin, however small, can make you more likely to get an infection. If you develop an infection (sometimes called cellulitis) the swollen part becomes red, hot and painful. You may have a high temperature, feel generally unwell and lose your appetite. Antibiotics are usually given to treat the infection and should be started immediately. You will usually need to take them for two weeks. It is important to see your doctor as soon as possible and (usually) stop all lymphoedema treatment. Remove compression garments, and rest the swollen part in a comfortable position with the whole limb supported along its length.

Tips to prevent skin damage and reduce the risk of infection

- Moisturise your skin gently every day with non-perfumed cream or oil. This helps it stay supple and in good condition.
- Avoid using needles (including acupuncture) or having injections in the affected area.
- Have your blood pressure taken on your unaffected limb.
- Wear gloves for washing up and other household tasks to avoid cuts.
- Wear gloves and long sleeves if you are gardening or handling animals so that you do not get scratched.
- Use insect repellent to prevent insect bites. If you are stung on, or near, the affected area, get medical advice.
- Use a thimble when sewing. To avoid cuts, use an electric razor when shaving hair from the swollen area.
- Cut your nails with nail clippers and use hand cream regularly.
- Never push back or cut your cuticles.
- Treat even small grazes and cuts straight away. Wash the area thoroughly and cover it if necessary. See your GP as soon as possible if you develop any signs of infection around the cut - redness, heat or inflammation.
- Excess heat can increase the swelling so try not to have your bath or shower too hot. It is also a good idea to avoid saunas, steam rooms and sunbeds and not to sit too close to a fire or other direct heat.
- To avoid burns when cooking or baking, wear long sleeves and use oven gloves.
- Avoid sunburn on the affected area.
- Use anti-fungal powder to prevent athlete's foot.
- See a chiropodist for foot and nail care if you need extra help and let them know you have lymphoedema. Make sure you wear well-fitting shoes to avoid blisters.

Controlling lymphoedema with compression garments

This is an important way of controlling swelling. Compression sleeves can be used for swollen arms and compression stockings for swollen legs. The garments work by compressing the swollen tissues and stopping fluid from building up. At the same time, they help to move the fluid to an area that is draining well. The support allows

the muscles to pump fluid away more effectively. The design of the garments means that more pressure is applied in certain areas to encourage the fluid to drain.

A compression garment should be worn all day, but can usually be taken off at night when you are lying down and resting. If you are travelling a long distance, especially by air, you should make sure that you wear your compression garment for the full length of the journey and for some hours afterwards.

Where to get compression garments

Your surgeon or lymphoedema specialist can prescribe compression garments for you. In many hospitals they are available from the breast care nurse or surgical appliances department.

The garments come in a range of shades to match different skin tones and there are hypoallergenic types for people with sensitive skin. Some garments are available 'off the shelf' or you may need to have them made to measure. We also have a list of [suppliers](#).

Wearing compression garments

Compression garments must be properly measured and fitted. If they are too tight the blood flow will be restricted.

If the garment causes pins and needles, pain, or a change in colour of your fingers or toes, it is too tight. Remove the garment as soon as you notice any of these signs and ask for advice from the person who supplied it to you.

A sleeve, stocking or bra that is too loose will not control swelling and will need to be refitted. Ask for advice from your lymphoedema therapist.

Tips for putting on compression sleeves or stockings

- It is best to put the garment on first thing in the morning, preferably before getting out of bed, or as soon as possible at the start of your day.
- Start by turning the stocking or sleeve inside out as far as the wrist or heel. Pull the garment over your hand or foot and ease it up - a bit at a time. Make sure you don't pull it up by the top of the garment. Do not turn or roll the top over - this will restrict the blood flow and cause more swelling.
- A household rubber glove, worn on the unaffected hand, may help when putting on your compression garment. It also helps to hold onto something (so that you have something to pull against) when pulling the sleeve up your arm.
- If you find it difficult to put on, apply a little unperfumed talc to your arm or leg before fitting.
- Make sure there are no wrinkles or creases in the material when your garment is on.
- You may need to wear a glove or mitten as well as your sleeve if you have swelling in your hand.
- Don't try to put the sleeve on straight after a bath, as dampness makes it very difficult to get on.

- Moisturise your skin every day. It is best to do this at night after you have taken off your garment, rather than in the morning - cream makes the sleeve or stocking very difficult to put on.

You should be given at least two garments so you can have one in the wash. The manufacturer will supply washing instructions. Worn on alternate days, compression garments will last up to six months. If your sleeve or stocking no longer fits properly, contact your nurse or therapist.

When not to use compression garments

In some circumstances a compression garment should not be worn, for example if the skin is very fragile, or if there is an infection. Your doctor, nurse or lymphoedema specialist can advise you about this.

Compression garments should not be used on very swollen or misshapen limbs or where the skin is pitted or folded. In this situation compression garments can be harmful and will not help the swelling to go down. The material can form tight bands across the skin and even damage it. If in doubt ask your doctor, breast care nurse or lymphoedema therapist for advice.

Compression bandages

If your arm or leg is very swollen or misshapen it may be difficult to fit a compression sleeve or stocking. In this case, multi-layer, elasticated bandages are used as the first part of treatment.

A lymphoedema therapist, nurse or physiotherapist will usually put the compression bandages on for you daily. It may take two or three weeks of bandaging before it is possible to fit a compression sleeve or stocking. [Manual lymphatic drainage massage](#) or simple lymphatic drainage massage and bandaging are often combined with exercises and skin care to reduce the size of a badly swollen limb.

Limb positioning and movement

Careful positioning of an affected limb when resting or sitting can help to prevent more swelling. You can also use gravity to help drain away excess fluid. Avoid sitting with your legs down if you can, as this causes the fluid to drain into your feet and calves. Movement of your muscles helps to push fluid around the body, so regular gentle movement can help to prevent fluid from collecting.

These tips will help you to position your affected limb correctly.

If you have arm swelling:

- When sitting down, rest your arm fully supported on a cushion placed on the arm of a chair.
- Try not to rest your arm above shoulder height - it may reduce blood flow to your arm and increase discomfort.
- You might find it helpful to raise your arm slightly on a pillow when you are lying down.
- Avoid carrying heavy shopping or other loads with your affected arm.

- Be careful when you use your affected arm for activities that involve a lot of repeated stretching. Some people find that too much activity can make the swelling worse.
- Do not wear clothes or jewellery that are tight fitting.

If you have leg swelling:

- It is a good idea not to cross your legs when you are sitting.
- Don't sit with your legs down for long periods - either lie with your legs up on a settee, or have them fully supported on a footstool.
- Try not to stand still for long periods of time. If you have to stand, do the following exercises to stimulate the pump action of your muscles:
 - Raise yourself up on to your toes frequently to tense and relax your calf muscles.
 - Shift your weight from one leg to the other and transfer your weight from heels to toes, as if walking on the spot.

Exercises and lymphoedema

Gentle exercises play a vital part in preventing lymphoedema. Your exercises will have more effect if they are done when you are wearing your compression garment.

About exercises

Exercises help in three ways, they:

- help drain away lymph and reduce swelling
- maintain or improve flexibility in your joints
- improve your posture.

However, too much exercise can increase swelling. If you are doing too much, your skin will become red, sticky and hot. Exercises for lymphoedema should always be gentle and feel comfortable. Do your exercises gradually and regularly so that you build up a regular routine. Try to do exercises that you enjoy.

Don't forget that many daily tasks can be thought of as exercise. Carrying too much weight with your affected arm can make the swelling worse, so bear this in mind when carrying handbags, luggage or shopping. Long periods of exercise and activity can also increase the swelling. Try to break up long and busy days with times of resting with your limb supported.

The right amount of exercise or activity will vary from person to person. It is a good idea to monitor the swelling while doing any exercises or after carrying out any daily activities. You can then avoid anything that makes the swelling worse.

It is also helpful to discuss the types of exercise that will help you, with your lymphoedema therapist, physiotherapist or nurse. If any exercise makes you more breathless, makes you uncomfortable or seems to make the swelling worse, **STOP** doing that exercise and ask for professional advice.

Arm swelling

Here are some simple exercises to reduce arm swelling:

- Sit comfortably and support your arm at shoulder height on pillows.
- Make a fist and then stretch your fingers out straight.
- Repeat this exercise as many times as feels comfortable.
- Also with your arm supported, try bending and straightening your arm at the elbow.
- Watch your posture, and check in a mirror that your shoulders are level.
- Practice shrugging and then dropping your shoulders slowly to the count of five.
- Slowly circle your shoulders in one direction, then the other.

Leg swelling

For leg swelling, try sitting with your leg up, making sure it is supported behind the knee. Do the following exercises at regular intervals while you are resting:

- Move your foot at the ankle to pull your toes up and then point them down.
- Bend and straighten your leg at the knee.

There are many other exercises that may help you. What is right for you depends on your agility and general condition.

If you have lymphoedema, it is very important to seek help from your lymphoedema specialist or therapist before starting an exercise programme.

Manual lymphatic drainage (MLD)

About MLD

A very specialised type of massage called **manual lymphatic drainage** (MLD) is an important part of the treatment of lymphoedema. To be effective in treating lymphoedema, it is important to use the correct technique. The aim of the massage is to stimulate or move the excess fluid away from the swollen area so that it can drain away normally. Massage also encourages and improves drainage in the healthy lymphatics (which helps keep fluid away from swollen areas).

Manual lymphatic drainage differs from ordinary massage - it is very gentle and aims to encourage movement of lymph away from swollen areas. MLD is particularly useful if there is swelling in the face, breast, abdomen, genitals or elsewhere on the trunk.

As this is a specialised form of massage, it should be given only by a trained therapist. There are some other different techniques including the Vodder, Földi, Leduc or Casley-Smith methods. Therapists should be trained in at least one of these.

Increasingly, MLD is provided by the NHS at lymphoedema treatment clinics. However, it is not yet available at all centres. If you are having difficulty finding a qualified MLD therapist, you can contact [MLD UK](#), who keep a register of their members.

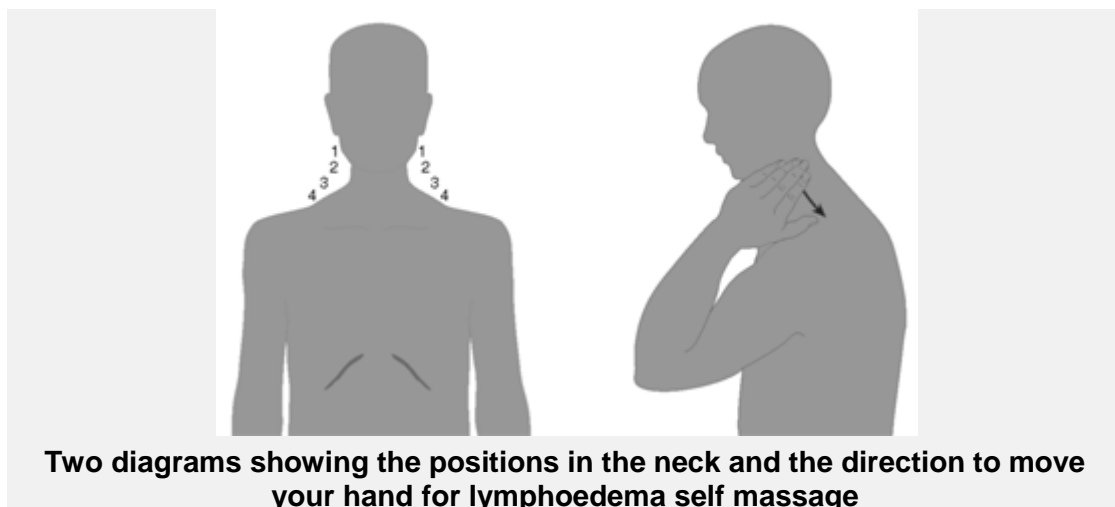
Simple lymphatic drainage (self massage)

Once you have been taught the techniques you can do a simplified version of MLD yourself at home. This is sometimes called **simple lymphatic drainage** (SLD). You use your hand very gently to move the skin in a particular direction. The massage is done without any oils or creams. If your skin is sticky and your hand does not move freely, a little talcum powder may be helpful. If you find that the skin is red when you have finished, then the movement is too hard.

It is often easier if your partner or a friend also learns the technique, so that they can help you in any areas you cannot reach. Your lymphoedema therapist, physiotherapist or nurse will be able to show you or your partner (or friend) the technique.

The diagrams and explanations below should also help. They are intended as a guide only when you are doing your SLD. You must be properly taught these techniques before you start.

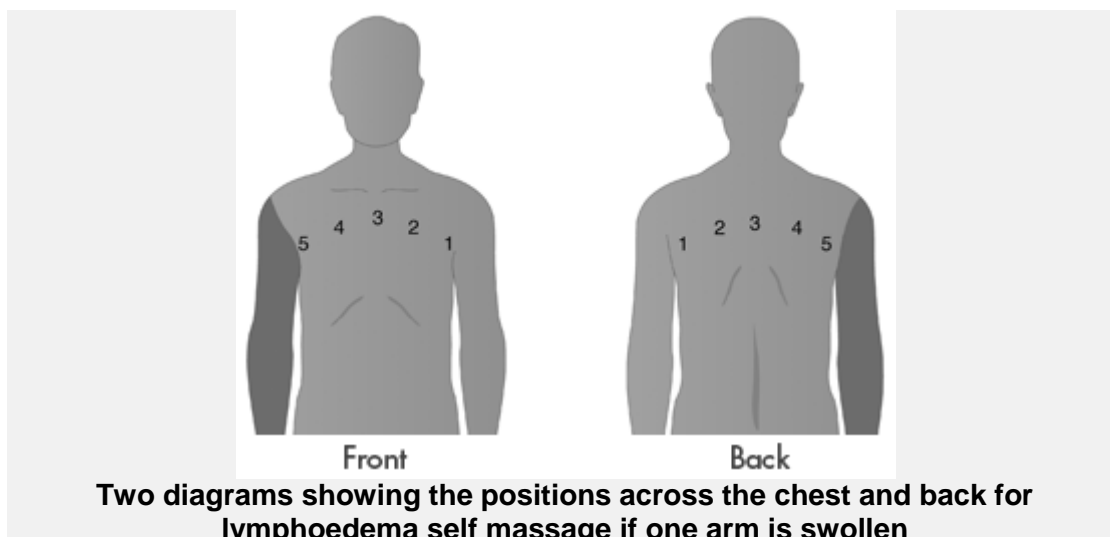
Massage 1 - for both arm and leg swelling



The massage aims to stimulate the flow of lymph in the body generally.

- Place your fingers, relaxed, on either side of your neck at position 1.
- Gently move the skin in a downwards direction, towards the back of your neck.
- Repeat 10 times at position 1, 2 and 3.
- At position 4 (on the top of your shoulder) use a gentle movement around the front of your neck in towards the top of your breastbone (where the collarbones meet).
- Repeat 5 times.
- If you have a short neck you may not be able to massage the neck in four places. If this is the case, miss out position 3.

Massage 2 - for swelling of one arm

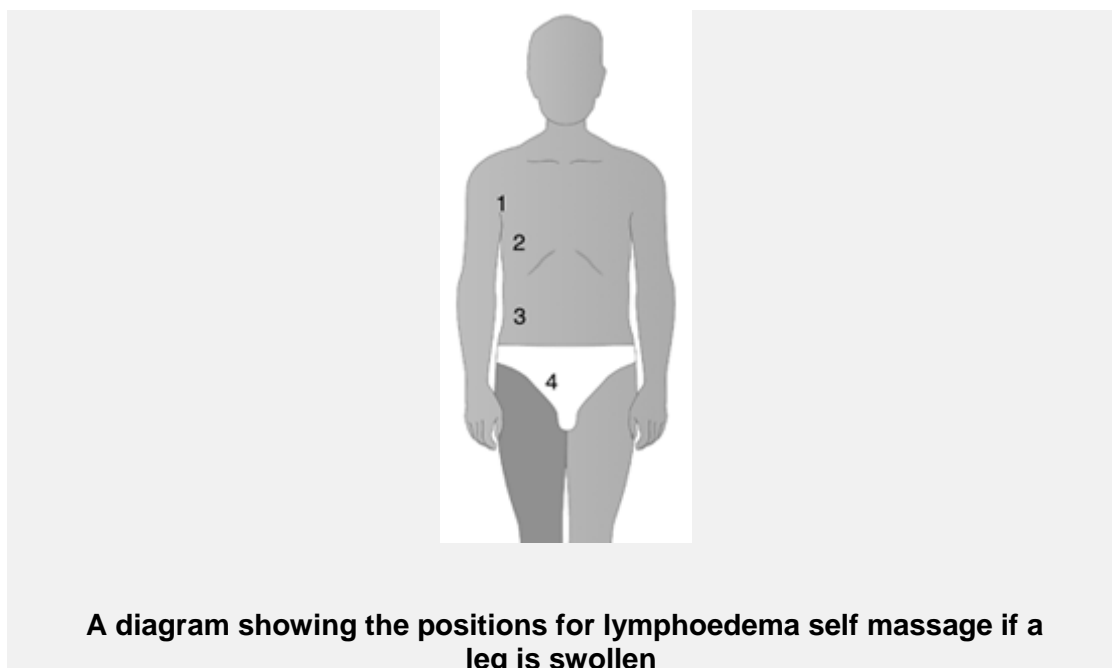


The aim of this massage is to stimulate the lymph channels on the trunk to clear the way ahead so excess fluid can drain away.

The skin is always moved away from the swollen side. You will find it easier to start with one hand, and then swap to the other as you move across the body.

- Starting in the armpit on the non-swollen side (position 1), use light pressure to gently stretch the skin up into the armpit. Your hand should be flat and not slide over the skin. Repeat 5 times.
- Next, at position 2, use a light gentle movement with the whole of the hand to slowly stretch the skin towards the non-swollen side, with a slow rhythm. Repeat in the same area 5 times.
- Repeat the same movements at position 3.
- Swap hands, and repeat the movements 5 more times at position 3 with your other hand, as this position is very important for lymphatic drainage. This time, the movement with your fingers is a slight pull to move the skin towards the non-swollen armpit.
- Repeat movements 5 times at position 4, then 5.
- If you have the help of a partner or friend the massage can be repeated across the back, starting again from the non-swollen side (position 1).

Massage 3 - for swelling of one leg



The aim of this massage is to clear a path ahead of the affected leg to allow excess fluid to drain away.

- Starting at the armpit on the same side as your affected leg (position 1), use light pressure to stretch the skin up gently into the armpit. Your hand should be flat and gently resting on the skin, not sliding over the skin. Repeat 5 times.
- Repeat 5 times each at chest level (position 2), waist level (position 3), then at your lower abdomen (position 4). Each time you will be gently pushing the skin up towards the armpit on the same side as the swelling.

Hand-held massagers

Hand-held massagers may be useful for people who have restricted movement of their hands, perhaps due to arthritis. However, it is a good idea to talk to your lymphoedema therapist before buying a massager.

Deep breathing exercises

Before and after MLD and SLD, breathing exercises can help to stimulate lymphatic drainage. Use the following simple exercises:

- Sit upright in a comfortable chair or lie on your bed with your knees slightly bent. Rest your hands on your ribs.
- Take deep breaths to relax.
- As you breathe in - direct the air down to your abdomen, which you will feel rising under your hands.

- Breathe out slowly by 'sighing' the air out. While breathing out, let your abdomen relax in again.
- Do the deep breathing exercises 5 times. Have a short rest before getting up to avoid getting dizzy.

Compression pumps and lymphoedema

Only a few people with lymphoedema will need to use a compression pump. They can be used as part of the treatment programme to help with certain sorts of swelling. You will be shown how to use the pump and your physiotherapist or nurse will be able to answer any questions you have about it.

If you are advised to use a compression pump, see if it is possible to borrow a pump from your local hospital. They are expensive to buy.

Before you use the pump, it is very important to carry out SLD or have MLD to your trunk and at the root of the affected limb. This is to drain lymph from these areas before the pump moves more fluid out of your affected limb.

The pump operates by electricity from the mains, and is made up of a power unit and an inflatable sleeve, which you put on your arm or leg. Various sizes of sleeve are available. When you switch it on, the sleeve will gradually pump up for a few minutes, then deflate for a few minutes. Low pressures are always used (never more than 40mm Hg). Do not use higher pressures than this, as it will not help to reduce the swelling and can make it worse.

While you are using the pump you should remove your compression garment, but put it back on as soon as you have finished.

Tips for using a pump

- Do not use the pump if you have an infection or inflammation in the affected limb.
- When using the pump, support your arm or leg on the arm of your chair or rest your leg up on a settee or bed. This will help with drainage.
- If you feel pain - **STOP** and consult your doctor.
- Watch for any increase in swelling or thickening at the top of the limb where the pump sleeve stops. If this happens, ask for advice.

Breast or chest lymphoedema

Compression bras and vests

Compression bras and specialist vests are available for breast or chest lymphoedema. They often need to be made to measure to make sure that they fit properly. Your lymphoedema specialist can help you to get the right garment for your situation.

You may also need to wear a compression sleeve to stop the fluid moving from one area to another and to help to improve drainage. Compression bandaging is not often used to treat lymphoedema of the breast or chest area.

Wear loose clothing

Clothes that are too tight can act like a tourniquet and may prevent lymph from draining. If your bra is too tight around the chest or if the straps dig into the shoulders and under the arm this can block the flow of lymph out of the chest. Try to wear a bra that has wide and flexible bands around the chest and shoulder straps. It's also very important to make sure you have the right cup size. Try to avoid clothing with tight waistbands.

Some breast prostheses are very heavy and can apply pressure to the chest area and may make the shoulder straps on a bra dig in. If you need to wear a prosthesis try getting a lightweight one. Your lymphoedema therapist should be able to advise you about bras and breast prostheses.

Manual lymphatic drainage

Manual lymphatic drainage (or self-massage) is an important part of treatment for breast and chest lymphoedema. Your therapist can give you more information about this.

Kinesiotape

A newer development is the use of kinesiotape. This is a special stretchy tape that is applied directly onto the skin. It gently lifts the top layer of skin which allows the superficial lymph fluid to flow more easily. The tape is waterproof and can be worn for several days at a time. Again, your lymphoedema therapist can tell you more about this.

Lymphoedema in other parts of the body

Head and neck lymphoedema

Lymphoedema of the face, neck or head is usually managed with massage. Compression garments are not often used. However, there is a facial compression garment, which can be worn at night.

Genital lymphoedema

If you have lymphoedema of the scrotum, wearing a scrotal support may help to control the swelling. If your penis is swollen, bandaging may help and you can be taught how to do this for yourself. More companies are beginning to supply specialist garments for genital lymphoedema. Your specialist can advise which products might be helpful in your situation.

Surgery for lymphoedema

It is rare for surgery to be used for lymphoedema, although it may sometimes be used to reduce swelling around the face or genital areas.

Surgery to an affected arm or leg will not mean that you can do without the other types of treatment described in this booklet. You will need to continue with these treatments after your operation.

Diet and lymphoedema

If you are overweight, your swelling will be far more difficult to treat. You will find that if you put on weight, your swollen limb will become more of a problem. Sleeves or stockings will not fit as well and may not be as effective.

For these reasons, it is helpful to keep your weight within the normal range for your height if possible. If you would like advice on diets or healthy eating, your hospital or community dietitian, or practice nurse may be able to help.

Some people find that certain foods, such as spicy and salty foods, can cause an increase in swelling; other people have found the same with alcohol, especially wine.

Follow-up - monitoring lymphoedema

It is important to have regular check-ups with your lymphoedema therapist or doctor, so that you can see what progress is being made. They will measure your arm or leg to monitor the effect of treatment.

You may find it helpful to keep your own progress chart. Progress may be slow, particularly at first, but there should be a noticeable improvement in the limb after a few weeks. If you are worried about any aspect of your treatment discuss it with your doctor, nurse or therapist.

Your feelings about having lymphoedema

Having lymphoedema may bring about a variety of feelings, which arise not only from the discomfort of the condition itself, but also from the cancer and its treatment, which caused the lymphoedema to develop.

Embarrassment

The lymphoedema swelling may be a constant reminder to you that you have had treatment for cancer - something you perhaps had hoped to forget as much as possible. If the swelling is severe, you may feel embarrassed and self-conscious about it.

Try not to shut yourself away. Almost certainly, the swelling is more noticeable to you than it is to others. If you are nervous about going out in public at first, ask someone you know to come with you. You will probably find that no one makes an issue of your lymphoedema.

As your lymphoedema becomes more under control, and as you get more used to it, you will almost certainly find that your feelings of embarrassment lessen. You will probably realise that true friends care for you because of the person you are, not for your appearance, and this will increase your self-confidence and make you feel more in control of your life.

If you have very obvious swelling, some people will inevitably be curious, especially children. Many people find it helpful to rehearse what they will say in such situations. Your lymphoedema therapist or nurse may be able to help you plan and practise your responses. Or you may prefer to talk about it with other people who have lymphoedema.

You could decide how much you want to say about your condition, whether to refer to your cancer or treatment. Once you have a prepared response, you are less likely to be thrown by any remark or question directed to you. You may even find yourself actively helping others to overcome any awkwardness they may feel.

Anger

You may feel very angry that you have to deal with the burden and inconvenience of lymphoedema. You may have been expecting to be feeling well again and leading a normal life.

If your lymphoedema began shortly after your cancer treatment, it may seem like the last straw, on top of all the physical and emotional upheaval caused by having cancer. It is quite natural for you to feel angry about it; you may find the anger becomes less as you get used to the daily treatment routine and the swelling begins to respond to the treatment.

Resentment

Having lymphoedema means extra effort in taking care of yourself. Following your treatment routine can take up a lot of time. You may feel resentful about this, especially if other people seem free to get on with their daily lives.

Try not to bottle up your feelings but talk to the people close to you about how you feel. Between you, you may come up with ways in which they can help. For example, someone could learn to carry out the lymphatic massage for you, give you lifts to your treatment centre or perhaps help with the shopping, so that you do not have to carry heavy loads.

Once you are used to the routine of treating your lymphoedema and following the guidelines for controlling it, you will probably find it less of a burden and feel more able to enjoy your normal activities. Some people find the swelling eases within a short time, while for others it can take many months, but don't give up - there is nearly always some improvement with treatment.

Depression

Lymphoedema is an ongoing problem and at times you are likely to feel low or depressed about your situation. You may find it helpful to talk to other people who have lymphoedema, and the [nurses at Cancerbackup](#) can give you information about support groups in your area. Your doctor may be able to refer you for help.

We have a separate booklet which discusses the [emotional effects of cancer](#).

Body image and sexuality

Lymphoedema may affect the way you feel about yourself, which may have a negative impact on your relationships with other people. People often need to feel happy with their bodies in order to have a fulfilling sex life. Fear that a partner - even a long-standing one - may be put off by the lymphoedema can make some people scared of physical relationships. The lymphoedema may also make it physically difficult to have sex.

Often, talking about how you are feeling can help to relieve any worries you have about how you look. Some people are able to talk with their partner, others prefer to

discuss things with a counsellor or sexual therapist. Your doctor or nurse can make a referral to a therapist for you if this would be helpful.

Our booklet on sexuality and cancer discusses these issues and how to cope with them in more detail.

Questions you might like to ask your doctor

You can fill this in before you see the doctor or surgeon, and then use it to remind yourself of the questions you want to ask, and the answers you receive.

1. _____

Answer _____

2. _____

Answer _____

3. _____

Answer _____

4. _____

Answer _____

5. _____

Answer _____

JASCAP : We need your help

We hope that you found this booklet useful.

To help other patients and their families we need and intend to extend our Patient Information Services in many ways.

Our Trust depends on voluntary donations. Please send your donation by Cheque or D/D payable in Mumbai in favour of "JASCAP".

Note for Reader

This JASCAP booklet is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through JASCAP is not a substitute for professional care and should not be used for diagnosing or treating a health problem or a disease. If you have, or suspect you may have, a health problem you should consult your doctor.

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