

The ROYAL MARSDEN

NHS Foundation Trust

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# Lymphoedema

*A guide for cancer patients*

Patient Information



**NHS**

## Foreword

This is one of a series of booklets written to provide information for patients and their relatives. It is impossible to include everything you may need to know. Your doctor or nurse will be able to answer specific questions.

This booklet has been prepared by lymphoedema therapists with input from doctors and other healthcare workers who are experts in their field as well as patients.

We hope you find it helpful and would welcome your comments so that the next edition can be improved further.



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## Contents

<b>Introduction</b>	1
<b>How do I contact a specialist?</b>	1
<b>The lymphatic system</b>	1
<b>What is lymphoedema?</b>	3
<b>When does lymphoedema occur?</b>	3
<b>What causes lymphoedema?</b>	3
<b>Some frequently asked questions</b>	4
<b>How is lymphoedema treated?</b>	6
<b>Taking care of your skin</b>	6
<b>Using the affected area</b>	10
<b>Compression therapy</b>	12
<b>Lymphatic drainage</b>	15
<b>How will my progress be monitored?</b>	16
<b>What changes should I report to my therapist or G.P.?</b>	17
<b>How will lymphoedema affect my life?</b>	17
<b>How can I help myself?</b>	20
<b>Notes/Questions</b>	22
<b>Where can I get help?</b>	25
<b>Sources of information and support</b>	26

## Introduction

Lymphoedema may develop after surgery or radiotherapy to treat cancer. It may affect a limb or any other part of the body.

This booklet contains:

- Information about the causes of lymphoedema
- Answers to some of the most frequently asked questions.
- A description of possible treatments.
- Advice about lifestyle and self-management

We hope it will help you, your family and friends to understand lymphoedema and get the best results from treatment.

Various people may help with your treatment, such as your hospital doctor, a lymphoedema therapist, physiotherapist, occupational therapist, family doctor (GP) and dietician. There is a page at the back of this booklet for their names and phone numbers, so you can contact them easily if you need help or advice.

Lymphoedema may also occur as a primary condition (see page 3). Much of the information in this booklet, for cancer patients, is also relevant for people with primary lymphoedema.

## How do I contact a specialist?

If you need to be referred to a lymphoedema specialist, your hospital doctor or family doctor can do this. Alternatively, you may like to find out if there is a specialist in your area. You can get names and addresses of lymphoedema services and therapists from the Lymphoedema Support Network (see page 26)

## The lymphatic system

The lymphatic system is made up of organs, such as the tonsils, thymus and spleen, and a network, of nodes, (glands) and vessels (tubes), which extend throughout the body (see diagram 1). The lymphatic vessels contain fluid called lymph. Lymph is a colourless fluid that forms in the tissues of the body.

There is a continuous flow of fluid within our bodies. It passes from the body tissues into the lymphatic system. Here the fluid is filtered through lymph nodes and then enters the bloodstream. This constant flow balances the amount of fluid in different parts of the body (see diagram 2).

The lymphatic system also makes cells called lymphocytes, which help the body fight infections. Lymphocytes also circulate in the blood, but are concentrated in the lymph, which forms part of the body's defence system.

Diagram 1

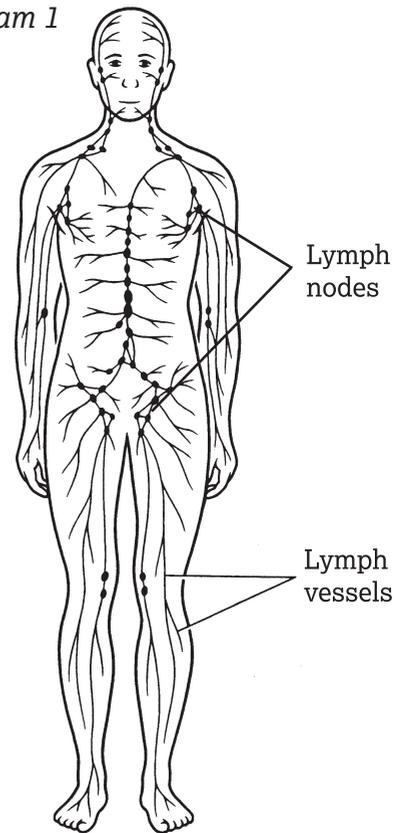
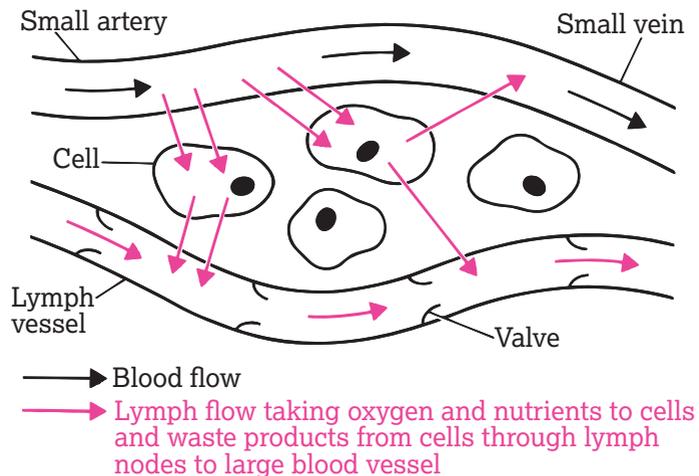


Diagram 2



## What is lymphoedema?

Lymphoedema is swelling (oedema) in the tissues beneath the skin which occurs when lymph can't drain away.

Lymphoedema can affect any part of the body including the head, neck and genitals. However, it most commonly affects a limb and sometimes the adjoining area of the body and / or breast.

Lymph is a colourless fluid that forms in the tissues of the body. It normally drains back into the blood circulation through a network of vessels and nodes called the lymphatic system. Lymph nodes act as filters removing dead or abnormal cells, including cancer cells and bacteria, playing an important part in the body's defence against infection. There are hundreds of lymph nodes in the body. They are found in clusters in the head and neck region, under-arms (axillae), groin, pelvis and abdomen. As lymph returns to the circulation, it filters through these nodes draining into larger lymph vessels in the body which then join the main circulation.

## When does lymphoedema occur?

Lymphoedema may be inherited; that is it can run in families. It can be due to under development of the lymphatic system that can be evident at birth but may not show up until later in life. Sometimes it may occur without any family history and with no other obvious cause. This is called primary lymphoedema.

More commonly lymphoedema may develop following an operation or radiotherapy to areas of the body where lymph nodes are present to treat cancer. It may occur immediately after treatment or many years later. It can also occur as a result of infection or trauma. This is called secondary lymphoedema.

## What causes lymphoedema?

Lymphoedema may appear when lymph vessels or lymph nodes are affected as a result of cancer treatment. Following surgery or radiotherapy to lymph node areas, scar tissue is formed and lymph drainage routes from part of the body may be reduced.

The situation is similar to that of a river, which has been dammed. Water builds up behind the dam, overflows the banks of the river and, if the ground does not drain properly, it becomes waterlogged. In lymphoedema, flow of lymph is reduced through the scar tissue and builds up in the surrounding tissues causing the area to become swollen.

## Some frequently asked questions

### Can lymphoedema be treated?

Yes, there are several ways of treating lymphoedema, discussed later in this booklet. Despite some scarring of the lymphatic system, some fluid does still drain away. However, it needs to be encouraged to find extra pathways through which to do this.

All treatments aim to restore the balance between the rate at which lymph is produced and the rate at which it drains away. Understanding the condition and receiving advice are both important.

### Why do some people develop lymphoedema and others do not?

At present no one can explain why some people develop swelling and not others. On-going research suggests that there may be factors, other than scarring, which affect the development of lymphoedema. Further research into this area is needed.

### Is all swelling lymphoedema?

No, there are many reasons why swelling may develop. It is quite usual for swelling to occur immediately following surgery and/or radiotherapy. This can happen as part of the healing process and should settle in time. If you have swelling or are concerned contact your hospital doctor for advice.

### Does lymphoedema mean the cancer has returned?

When swelling first appears, many people are worried that their cancer has returned. Although recurrent cancer can cause lymphoedema, this is not often the case. Do not be alarmed if you notice an area of swelling, contact your hospital doctor for advice.

### Why can't the fluid be drained off?

This sort of swelling does not often collect as a single pool of fluid. Instead it is spread throughout the tissues, making drainage difficult. Also lymph is formed in the tissues all the time and so would be replaced as quickly as it is drained.

### Would diuretics help?

As a rule diuretics (water tablets) have little effect on this type of swelling. They tend to 'dry out' other parts of the body, rather than the lymphoedema, which isn't good for your general health.

### Can the swollen areas be cut out?

An operation on the swollen areas won't remove the cause of the swelling so lymph will still be produced and the lymphoedema is likely to return. The long-term benefits of this type of surgery are unproven.

New surgical techniques are considering whether the lymphatic system can be reconstructed or if a lymph node can be successfully transferred from another part of the body. These techniques require more research before they can be considered successful in the management of lymphoedema.

Sometimes after severe swelling has been reduced by treatment, plastic surgery may be carried out to remove excess skin folds. However, this is not always recommended and should be discussed with your doctor.

### Can my lymphoedema be cured?

Lymphoedema can't be cured because glands and lymph vessels cannot be repaired after treatment for cancer. However, for many people lymphoedema treatment can reduce the swelling considerably and this reduction can be maintained through self-management.

However successful your lymphoedema treatment and management is there will always be a risk that some swelling will return. You should continue with all aspects of your self-management as advised by your Lymphoedema Therapist, including the wearing of your garments and practise any lymphatic drainage techniques and exercises that you have been taught.

You may be able to recognise what activities make your swelling appear worse and, by limiting these, feel in control of your lymphoedema.

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## How is lymphoedema treated?

There are four aspects of treatment as follows:

- taking care of your skin
- using the affected area
- gaining external support from compression garment or bandages
- using lymph drainage techniques

Occasionally other treatments may be used and your treatment will be tailored to suit you. You may not need all the available treatments, or you may receive them at different times or in a different order.

### Taking care of your skin

Taking care of the skin over the affected area is important as it may help to reduce the risk of getting an infection.

Whether you bath, shower or strip-wash, the swollen area should be washed thoroughly each day. Take care not to have the water too hot as this will increase the blood supply and may make the swelling worse.

Most people are good at washing hands, but it is also important to dry thoroughly between your fingers and under rings. Feet are more difficult to reach. If it is a problem, ask someone to wash and dry between your toes. There are some aids available to help out, if necessary, so please ask. Fungal infections, such as athlete's foot, commonly occur between the toes. These should be treated as soon as possible.

Other areas that may need special attention when washing and drying are:

- under the breasts
- behind the ears
- in the groin and genital area
- any other deep creases which may have been caused by swelling, or scars from an operation.

Stretched skin can become dry and cracked, making it prone to infection. Using a simple moisturiser daily to keep the skin supple can help to prevent this. Choose an unperfumed cream or lotion as highly perfumed ones can sometimes cause irritation.

### Infection

Infection can cause further scarring of the tissues, worsen the swelling and make your lymphoedema more difficult to treat.

Try to avoid cuts and scratches to the affected area. If they do occur, wash the area thoroughly and apply a simple antiseptic cream or lotion. If a cut is deeper and needs to be covered, use the minimum of tape to secure a dressing.

If you notice any redness of the area or it's slow to heal, contact your family doctor as soon as possible. You may need some antibiotics if you have developed an infection.

If a swollen area becomes hot, red and painful, you may have developed cellulitis. You may also develop flu-like symptoms and feel quite unwell.

**Antibiotics must be given straight away.** Contact your family doctor and ask for a house call rather than wait for an appointment at the surgery. Rest and elevate the affected part of your body. If the swollen area is painful do not use your compression garment until the cellulitis has got better. You can take pain relief such as paracetamol for discomfort. Usually symptoms get better after a course of antibiotics.

Some people develop cellulitis repeatedly with no apparent cause – no cuts or bites can be seen. If this happens and you have two episodes in a year, you may be offered preventative (prophylactic) antibiotics. A low dose will be prescribed for one year or longer.

Always make sure you have enough antibiotics whenever you are away from home, especially if you travel abroad on holiday.

### How to help yourself

**Try to avoid** things that could lead to an infection.

Injections or infusions (drips) into the swollen area.

Having blood taken from the swollen limb (or giving blood, if you are a donor)

Cuts and grazes

Insect bites or stings

Scratches or bites from pets

Non-essential operations on the swollen area

Acupuncture in areas where swelling is present

**Try to avoid** changes in temperature, which could lead to an increase in swelling.

Very hot or cold baths and showers

Burns

Sunburn

Direct contact with ice and snow

Deep tissue massage in areas where swelling is present

**Try to avoid** constriction of the swollen area, which may further reduce the lymph drainage channels.

Having your blood pressure taken repeatedly on a swollen arm

Tight clothing

Tight jewellery, such as rings, bracelets, watches

You can take some simple precautions to prevent those problems when going about your daily routine.

### General advice:

- Take care when cutting or filing the nails on your affected limb. If you have difficulty with this, arrange to see a manicurist or chiropodist.
- Use an insect repellent if you are prone to bites, especially during the summer. Always make sure your pets are free from fleas.
- Use an electric shaver to remove unwanted hair – depilatory creams can cause irritation and razors can nick the skin. Epilators, electrolysis, waxing and laser can all damage the skin.

If your **arm** is affected:

- Wear gloves when you are washing up or gardening.
- Use oven gloves when handling hot dishes.
- Use your unaffected hand to remove packages from the freezer.
- Use a thimble when you are sewing.

If your **leg** is affected:

- Wear long trousers when you are gardening.
- Do not go barefoot, especially on the beach, around swimming pools or in communal showers.
- Use a protected blade or electric shaver to remove unwanted hair from your legs.

If your **face** or **neck** is affected:

- Use an electric shaver.
- Do not wear tight collars, ties, scarves or necklaces.
- Use creams and make-up especially for sensitive skin.

## Using the affected area

Swelling may restrict movements of your arm, leg, head and neck. Try to use the affected area as normally as possible because this activity will help lymph drainage. Your lymphoedema therapist may suggest some simple exercises designed to reduce swelling. If you have limited movement of a joint or limb, the physiotherapist may be able to help you.

You will be given advice about specific everyday activities. If you have difficulties reaching the floor or holding a pen or cutlery, for example, the occupational therapist may be able to help you.

If your arm is affected try to avoid any sudden, strenuous movements, such as pushing, pulling or lifting heavy objects. You may strain your muscles, which can make the swelling worse.

Try not to swing your arm when you are walking because this can make your hand swell. Put your hand in a pocket or hold on to the strap of a shoulder bag (carried on your unaffected side) instead. Gentle movement of your arm alternating with a period of rest is best. If you are using a sling you may be tempted to leave your arm in that one position. Lymph can pool at the elbow and cause stiffness of the joint. When you are relaxing rest your arm outstretched on a cushion at the level of your heart. This will limit the formation of lymph.

If your leg is swollen, try to avoid standing still for long periods or sitting with your feet on the floor. Rest your leg outstretched on a chair, or stool, supported by pillows. Your foot should be level with your bottom and the back of your knee supported. This will limit the formation of lymph.

## Exercise

Exercise is good for your lymphatic system. Muscle activity encourages lymph to drain, which can help reduce swelling.

You do not need to take part in any specific activity or sport. Gentle exercise such as walking, cycling or simple range of movement exercises can help lymph to flow.

If you are returning to an activity that you have not done for some time, or plan to take up a new form of exercise, remember to start gently and progress gradually to avoid straining yourself.

Too much strenuous activity, particularly if you start suddenly, may cause your swelling to increase. This is because blood flow is increased and more lymph is produced.

Progressing slowly also means you can monitor your limb for any changes. We all have a different level of fitness and ability to exercise. Find the right level of activity for you.

If you've been fitted with a compression garment, you should wear it when exercising.

Swimming is a good all round form of exercise. It allows ease of movement because the water supports swollen limbs when you're not wearing your compression garments and places less stress through your joints. If you cannot swim, you can still benefit from doing exercises in the water. You should shower afterwards to reduce the risk of infection. Apply extra moisturiser as chlorine or salt causes drying of the skin.

Exercise can also help to maintain a healthy weight. Being overweight can contribute to both lymphoedema and the risk of infection.

Rest is also important. Remember to support your limb in the correct position when you're relaxing.

If you have any questions about exercise, or a particular sport, please contact your lymphoedema therapist for more advice.

If you have any pre-existing medical conditions, please check with your GP before returning to a previous activity or starting a new exercise programme.

## Eating and talking

You may have difficulty eating, talking or keeping your mouth clean if part of your face or neck is swollen. Your lymphoedema therapist may refer you to a dietician and/or speech and language therapist or oral hygienist, all of whom may be able to help. A physiotherapist may be able to provide advice about exercises if you have stiffness of your face or neck muscles.

If you find your appearance distressing, you may find it helps to discuss this with your lymphoedema therapist, who may be able to refer you for counselling.

### Sexual relationships

There is no reason why you should not continue with sexual activity if you wish, even if your genital area is swollen.

Sexual activity increases the blood supply to the genitals and this may cause an increase in swelling. Men who have genital swelling may have difficulty getting an erection, and also with penetration. Advice and support is available if necessary. Personal hygiene is important to reduce the risk of infection so pay special attention to the care of this area if swelling is present.

You may find you lose any desire to have sex. This isn't unusual during a period of illness or anxiety.

If you have particular concerns you wish to discuss, speak to your lymphoedema therapist.

### Compression therapy

Compression therapy provides graduated, even pressure, which will not constrict your limb. It will be carefully chosen, with you, by your lymphoedema therapist. You may always need to wear a compression garment, particularly during times of increased physical activity. Compression therapy can be provided in two ways, either compression garments or compression bandages.

### Compression garments

Most people with lymphoedema are fitted with a compression garment for swelling in the arms or legs. Firm, supportive underwear may be helpful for breast, truncal, or pubic swelling. There are also garments available for facial swelling.

The garment is designed to limit the formation of lymph. It provides resistance against which the muscles can pump and move lymph more effectively. Limb size shouldn't increase and sometimes may be reduced.

You should put on your garment first thing in the morning and remove it last thing at night. When you start wearing the garment it may feel strange. You may like to wear your garment for a few hours on the first day, gradually increasing the time. By day three or four, you should be wearing it all day.

Your garment may be difficult to put on but your lymphoedema therapist will help you with this and show you the best way. It should become easier with practice. You may find that wearing ordinary household rubber gloves allows you to get a firmer grip. If you continue to have difficulty, you may be able to obtain a special applicator.

**Once your garment is on it should feel firm, supportive and, above all comfortable. If you notice a change in the colour of your fingers or toes or any new tingling, numbness or pain in your limb/affected area, remove your garment straight away. If you have any problems at all, with the fit or comfort of your garment, contact your lymphoedema therapist.**

You will be given one garment and a second garment will be requested from your family doctor (GP) on prescription so you can wash one and wear one. Your garment should be washed, every two to three days, at 40 degrees or less and allowed to dry naturally. Use a mild washing powder or liquid, such as one recommended for woollens or delicate fabrics, as detergents can damage the garments. Instructions may vary with the make of garment so check these carefully. Avoid the use of a fabric conditioner.

You will need replacement garments every six months because with daily wear they lose their compression over time. If you have any questions about your garment you can ask your lymphoedema therapist.

You will not have to pay a prescription charge for your compression garments once you have completed form FP92A to apply for a certificate which entitles people with a cancer diagnosis to free prescriptions. You may purchase additional garments at the full price if you wish.

## Compression bandaging

Compression bandaging is used to provide compression when:

- Conventional hosiery is not available for a particular size or shape of limb.
- The skin is fragile and may be damaged by putting on and removing hosiery.

Several layers of bandaging and foam pads will be applied to your limb to give even compression and to reshape it. The layers will also protect your skin. Your lymphoedema therapist will usually do the bandaging. Sometimes you may be taught to do this yourself.

A course of compression bandaging lasts for about three weeks. The bandages are either renewed every weekday, or twice weekly depending on the bandaging system selected for you. Your lymphoedema therapist will also check the condition of your skin each time you attend, when you can wash your limb. The first treatment usually takes about an hour and then each daily session may be between 30 minutes and one hour.

If you have been offered a course of compression bandaging, you will be given a card listing the dates and times of your appointments. You will be asked to bring a washcloth, soap, towel and your moisturiser, so you can wash your limb before it is re-banded.

While you are having compression bandaging, you will need to wear loose fitting clothes to allow for the bulk of the bandages.

If you are having your leg(s) bandaged, you should wear large lace-up shoes, such as trainers about two sizes bigger than usual. These will enable you to walk in comfort, safely and at a reasonable speed. Slippers aren't a good idea as they are unlikely to fit securely over the bandages. If you are unable to find suitable footwear, you may be offered a plaster shoe.

We do not recommend that you drive yourself to the hospital, whilst your limb is bandaged. If you choose to drive you must check that your motor insurance company covers you.

When you finish your course of treatment you will be fitted with a compression garment to maintain your limb size. We advise you to wear your garments during the day and at night for the first six weeks after treatment.

If you are offered a course of treatment with compression bandaging you will be given a leaflet containing more detailed information.

## Lymphatic drainage

Lymphatic drainage is sometimes termed 'massage' because it involves hand movements on the skin but it is very different from therapeutic or aromatherapy massage which can be performed on areas of the body not affected by swelling.

There are two types of lymphatic drainage which may be used to treat lymphoedema – **manual lymphatic drainage (MLD) and simple lymphatic drainage (SLD).**

Lymphatic drainage techniques provide regular stimulation of the lymph vessels under the skin. It encourages them to work harder and find new pathways to drain away the lymph using a milking or syphoning effect to move lymph away from the swollen area.

Treatment with MLD or SLD may be particularly helpful if you have swelling of your face, neck upper arm, thigh, breast, trunk or genitals.

### Manual lymphatic drainage

Manual lymph drainage (MLD) is a very special type of massage designed to stimulate the lymphatic system. The hand movements and sequences are adapted for each person. **It must be carried out by a qualified practitioner.** Ask your lymphoedema specialist if you might benefit from MLD.

If you would like to find out if there is a therapist in your area, contact **MLD UK** (see page 27).

### Simple lymphatic drainage

You may be taught a simple form of massage which you can perform yourself each day. This is simple lymphatic drainage.

The massage is based on the more complex technique of MLD and takes about 20 minutes. You should try to perform it at the same time each day so that your lymphatic system is stimulated regularly. You can carry out the massage with or without wearing your hosiery or bandages on your affected limb. The swollen area is never massaged when using this technique. Many people find it both convenient and relaxing to perform the massage at bedtime.

If you wish, your lymphoedema therapist can teach a relative or friend to do the massage for you. This can be particularly helpful if you need massage to your back.

### Compression pumps

If you have a compression pump and have found it helpful, you should discuss its continued use with your lymphoedema therapist. Mechanical compression pumps “squeeze” a swollen limb in a sleeve or boot which inflates and deflates at regular intervals. Lymph can be moved from a limb quite quickly but it may collect in the trunk of your body causing discomfort. Lymph may also return to the limb quickly when the pump is removed. However, a pump may help to soften the tissues of a limb and may be recommended by your therapist for this reason. New style compression pumps can mimic manual lymphatic drainage.

### Kinesiology tape

You may be advised to use a kinesiology tape which aims to encourage lymph drainage. Your therapist will discuss this with you.

## How will my progress be monitored?

Your progress will be checked at regular follow-up appointments to monitor your lymphoedema. You may be referred to a clinic closer to home if there is one. The time between these appointments may vary depending on your response to treatment. At each visit you will be able to discuss any problems or concerns related to your lymphoedema. The swollen area will be examined and may be measured. Your treatment may be revised and you may be given further advice about diet or activities.

Lymphoedema can often be stabilised and you may only need to visit the hospital once every six to 12 months.

In the long term you are the person who controls and monitors your lymphoedema. The time may come when your therapist may not need to see you again and will refer you back to your G.P.

## What changes should I report to my therapist or GP?

Contact your therapist or family doctor if you are concerned about anything but especially if you develop:

- **Signs of infection** - redness, heat, rashes, tenderness or pain affecting the swollen area or a raised temperature or flu-like symptoms.
- **Signs of problems with your circulation** – changes in the colour of the swollen area to white, blue or purple or pain or a sudden increase in swelling.
- **Signs of a worsening of your lymphoedema** – an increase in swelling or the formation of blisters, areas of weeping or discharge or any other skin changes, such as hardening of the skin.
- **Signs of changes in sensation or function of the area** – tingling, numbness **or** pain **or** clumsiness.

Your therapist or doctor will ask you what may have influenced these changes and discuss with you how best to deal with them.

## How will lymphoedema affect my life?

How lymphoedema affects your life may depend on which part of your body is swollen and to what degree. It may not prevent you from continuing with your usual lifestyle and activities. However, you may need to modify some aspect of your life if these involve a lot of activity, or inactivity, of a swollen limb.

Try to continue with your life as normally as possible but listen to your body. If any activity causes discomfort, approach it gently and with caution or don't do it.

If you have difficulty with activities such as washing up, cooking and getting washed or dressed, ask to see the occupational therapist. S/he can advise you about techniques and equipment to help.

When shopping, ask someone to help with heavy bags or split the shopping into lighter loads. Many supermarkets can arrange home delivery.

Lymphoedema is a chronic condition and not necessarily a disability, but if you think you may be entitled to a disabled driver's badge, please discuss this further with your G.P.

## Clothing and shoes

You may have problems getting clothing or footwear to fit you. Try to avoid tight clothing, or jewellery, which will prevent drainage of fluid because of pressure on lymph vessels.

A correctly fitting shoe is important if you have a swollen foot. A flat heeled shoe with a lace-up fastening is recommended to provide support and helps to limit the swelling. During bandaging treatment you may prefer to wear trainers. Some people cannot wear shoes of the same size on both feet. If you have difficulty getting 'odd' shoes, you can contact the Disabled Living Foundation. (address on page 26).

You don't have to stop looking smart because you have lymphoedema. If you enjoy dressing up and going out, you should continue. Your garment can be covered with long sleeves, gloves, trousers or long skirts, if you wish. Dark opaque tights or stockings can be worn over compression garments. Your lymphoedema therapist will be able to advise you about clothes and footwear.

## Relationships and feelings

Other people may ask about your lymphoedema. How you respond will depend on how you feel about the swelling yourself. It's quite usual to sometimes feel angry or fed up about your swelling and you may have negative feelings sometimes.

If you find your appearance distressing, you may find it helps to discuss this with your lymphoedema therapist, who may be able to refer you for counselling.

## Will changing my diet help?

Being overweight may affect your treatment for lymphoedema and your general health. If you are worried about your weight, discuss this with your lymphoedema therapist or family doctor.

There is no special diet for treating lymphoedema. Try to eat healthy, well-balanced, meals.

## What about going on holiday?

There is no reason why you should not go on holiday. If you are planning to fly long distances, and have been fitted with compression garment, you should wear it during the flight. Swelling may increase in a pressurised cabin. This should reduce after the flight. If your arm is swollen, it is advisable to avoid lifting and pulling heavy luggage.

If you are planning a holiday in a hot climate, any time of year, continue to take extra care of your skin:

- Use a sun protection cream, with a minimum of SPF 30. Sit in the shade or cover up with a hat, T-shirt or loose trousers. Remember you can get sunburnt through hosiery, even just walking around. Sunburn can result in increased swelling.
- Shower after swimming as both salt and chlorine can cause dryness.
- Use extra moisturiser. If the swollen area is exposed to the sun, the skin may become dryer than usual.
- Do not go barefoot on the beach, in the sea or around the swimming pool if your leg is swollen. This will reduce the risk of getting cuts, scratches and infections in your foot.

It can be hard to wear your garment on holiday in a hot climate but wear it as much as you can. You may find this easier during the cooler periods of the day. Chlorine in swimming pools and salt in the sea can affect compression garments so try to wear an old garment during these activities.

Heat may worsen your swelling – do not be alarmed by this. If possible, continue to wear your garment. Try to stay cool and rest when possible. Any increase in swelling should reduce on your return home.

Think carefully about where you are going on holiday – you may need to use an insect repellent. Remember not to have immunisations given into a swollen area or an area that may be at risk of swelling.

Remember when you're on winter holidays, such as skiing, the sun is even more deceptive, so don't forget your sun block.

Always remember to take your antibiotics with you if you are on long-term treatment or your doctor has told you you're at risk of developing cellulitis. If you think you may have an infection in your swollen area, go to a doctor straight away. You can check what medical help may be available to you in advance and make sure that you have sufficient medical insurance cover.

Activity holidays can be fun but do not spoil them by overdoing an activity you are not used to. Discuss this type of holiday with your therapist before you make arrangements.

Above all, enjoy yourself.

## How can I help myself?

You can help yourself by following the advice given to you by your lymphoedema therapist. The key points are:

- Take care of your skin, to prevent infection.
- Try to achieve a balance between exercise and rest.
- Do not use the swollen area excessively.
- Wear and care for your garment as instructed.
- Carry out any lymphatic drainage techniques you may have been taught.
- Tell your lymphoedema therapist promptly about any changes in colour, sensation, temperature or swelling.

Most importantly, attend your follow-up appointments. The encouragement you receive will help to keep you motivated to continue your treatment. Also any potential problems can be picked up at an early stage.

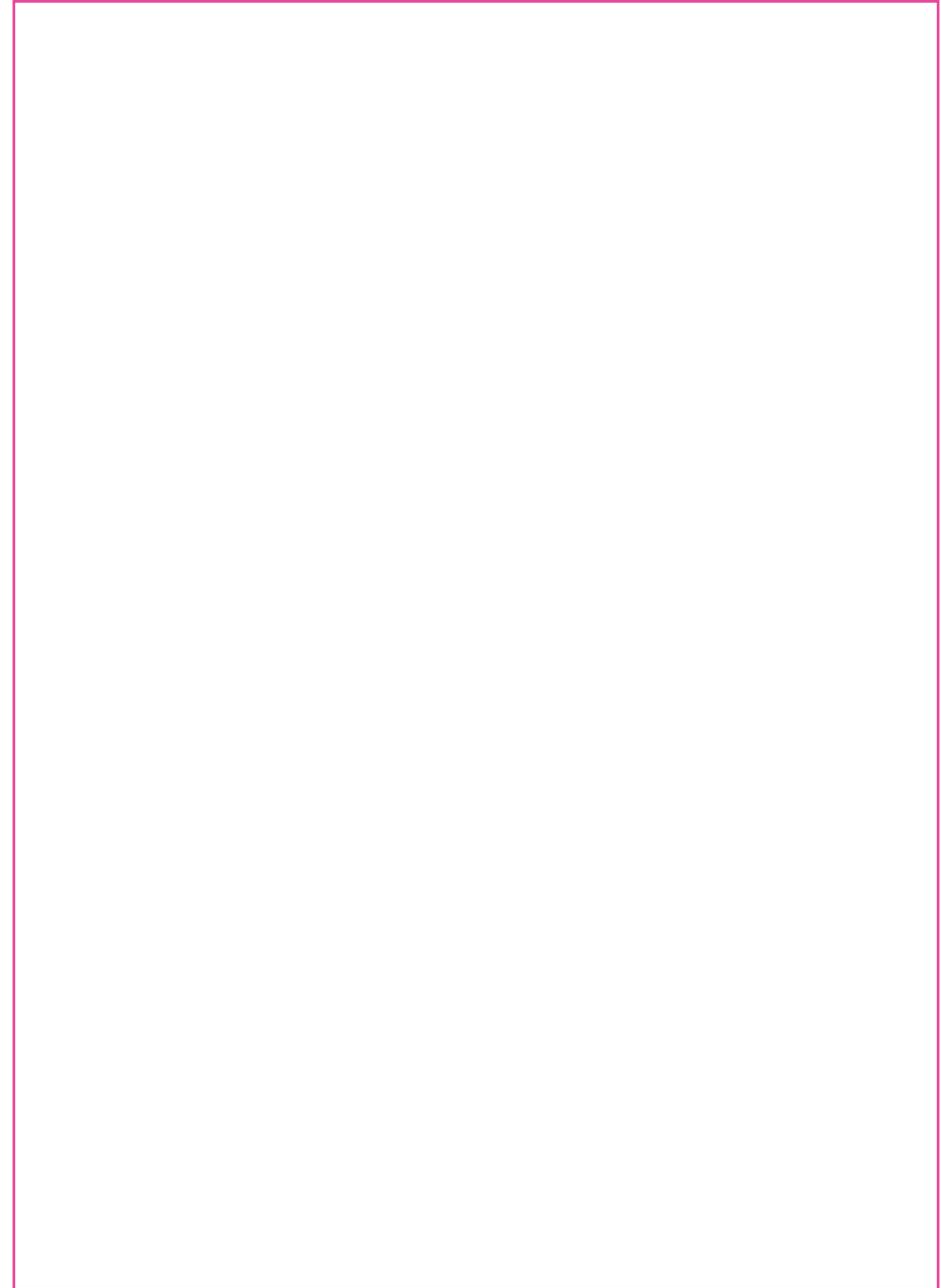
If you are concerned about anything between appointments, contact your lymphoedema therapist straight away so that you don't worry needlessly.

## Notes/Questions

You may like to use this space to make notes or write questions as they occur to you, so that you can ask the doctor or lymphoedema therapist next time you see them.



## Notes/Questions



## Notes/Questions

## Where can I get help?

If you have any queries about your illness or treatment or have any unexpected problems, please contact:

Your consultant (clinical oncologist)

\_\_\_\_\_

Or one of his/her team

\_\_\_\_\_

Your lymphoedema therapist

\_\_\_\_\_

Or a specialist nurse

\_\_\_\_\_

at \_\_\_\_\_ Hospital

Telephone number \_\_\_\_\_

Or your family doctor

\_\_\_\_\_

Telephone number \_\_\_\_\_

## Sources of information and support

### Macmillan Cancer Support

89 Albert Embankment  
London SE1 7UQ  
Tel: 020 7840 7840  
Freephone 0808 808 0000  
Website: [www.macmillan.org.uk](http://www.macmillan.org.uk)

Provides free information and emotional support for people living with cancer and information about UK cancer support groups and organisations.

Helps patients, their families and friends cope with cancer. Trained cancer nurses provide information, emotional support and practical advice by phone and letter. Over 50 publications on cancer, its treatment and practical issues of coping.

### Disabled Living Foundation

380-384 Harrow Road  
London W9 2HU  
Tel: Helpline (local rate) 0845 130 9177 (Monday – Friday 10am – 4pm)  
Textphone: 020 7432 8009  
Website: [www.dlf.org.uk](http://www.dlf.org.uk)

National resource for information about equipment to help people with a disability carry out daily living activities.

### Lymphoedema Support Network (LSN)

St Luke's Crypt  
Sidney Street  
London SW3 6NH  
Helpline: 020 7351 0990  
Fax: 020 7349 9809  
Website: [www.lymphoedema.org/lsn](http://www.lymphoedema.org/lsn)

### Breast Cancer Care

5-13 Great Suffolk Street  
London SE1 0NS  
Tel: Freephone helpline: 0808 800 6000  
Monday – Friday 9am – 5pm and Saturday 9am – 2pm)  
Website: [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk)

An organisation offering information and support to those affected by breast cancer and the effects of treatment.

### MLD UK

PO Box 14491  
Glenroths  
Fife KY6 3YE  
Tel: 0844 800 1988  
Website: [www.mlduk.org.uk](http://www.mlduk.org.uk)

An organisation which will help you to find a manual lymph drainage therapist in your area.

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Revised October 2014  
Planned review October 2016

This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from: The Royal Marsden Help Centre  
Freephone: 0800 783 7176  
Email: [patientcentre@rmh.nhs.uk](mailto:patientcentre@rmh.nhs.uk)

The Royal Marsden NHS Foundation Trust  
Fulham Road  
London SW3 6JJ

[www.royalmarsden.nhs.uk](http://www.royalmarsden.nhs.uk)

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No conflicts of interest were declared in the production of this booklet.

The information in this booklet is correct at the time of going to print.



The Royal Marsden publishes a number of booklets and leaflets about cancer care. Here is a list of information available to you.



### Diagnosis

- A beginner's guide to the *BRCA1* and *BRCA2* genes
- CT scan
- MRI scan
- Ultrasound scan



### Treatment

- Central venous access devices
- Chemotherapy
- Clinical trials
- Radiotherapy
- Radionuclide therapy
- Your operation and anaesthetic



### Supportive Care

- After treatment
- Coping with nausea and vomiting
- Eating well when you have cancer
- Lymphoedema
- Reducing the risk of healthcare associated infection
- Support at home
- Your guide to support, practical help and complimentary therapies



### Your hospital experience

- Help Centre for PALS and patient information
- How to raise a concern or make a complaint
- Your comments please
- Your health information, your confidentiality



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