

# Understanding lymphoedema





**“ I'd heard of Macmillan before I was diagnosed. But I didn't really have any idea of how extensive the support could be. ”**

Anne, living with lymphoedema



# About this booklet

This booklet is about lymphoedema. It is for anyone who has lymphoedema, or is at risk of developing it. This booklet may also be helpful for family members, friends or carers.

The booklet explains the signs and symptoms of lymphoedema and how you may be able to reduce your risk of developing it. It explains how lymphoedema is diagnosed and how it may be treated. There is also information about feelings, practical issues and money.

We hope it helps you deal with some of the questions or feelings you may have. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

## How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 106 to 114, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (pages 115 to 116).

### Quotes

In this booklet we have included quotes from people who have lymphoedema, which you may find helpful. The others are from people who have chosen to share their story with us. This includes Anne, who is on the cover of this booklet. To share your experience, visit **macmillan.org.uk/shareyourstory**

### For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

We have some information in different languages and formats, including audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

---

## Contents

Lymphoedema	<b>5</b>
Reducing your risk of lymphoedema	<b>23</b>
Treating lymphoedema	<b>31</b>
Other ways of treating lymphoedema	<b>65</b>
Coping with lymphoedema	<b>75</b>
Work and financial support	<b>85</b>
Your feelings	<b>91</b>
Further information	<b>99</b>



# Lymphoedema

What is lymphoedema?	6
The lymphatic system	8
How lymphoedema develops	14
Causes of lymphoedema	15
Signs and symptoms	17
Diagnosis	19

# What is lymphoedema?

Lymphoedema is swelling that develops because of a build-up of lymph fluid in the body's tissues. The lymphatic system usually drains the fluid away. Lymphoedema happens when the lymphatic system is not working properly. This may be because it is damaged by cancer, or cancer treatment such as surgery or radiotherapy.

Lymphoedema can develop months or even years after cancer treatment. It can happen anywhere in the body, but the most common place for lymphoedema to develop is the arm or leg. It can also happen in the chest, head and neck, or genitals.

Not all swelling is lymphoedema. Something else, like a blood clot, could be causing the swelling. You may need tests to find out what is causing it. The tests you have will depend on what part of the body is swollen. You may have scans, to see whether a cancer that is affecting the lymph nodes is causing the lymphoedema.

Your cancer doctor or specialist nurse will advise whether you are at risk of lymphoedema. There are things you can do to reduce the risk of lymphoedema developing, and they can show you how to check for any changes. They can also refer you to your local lymphoedema service for assessment.

You can find out more about ways you can reduce your risk of lymphoedema on pages 24 to 29.



# The lymphatic system

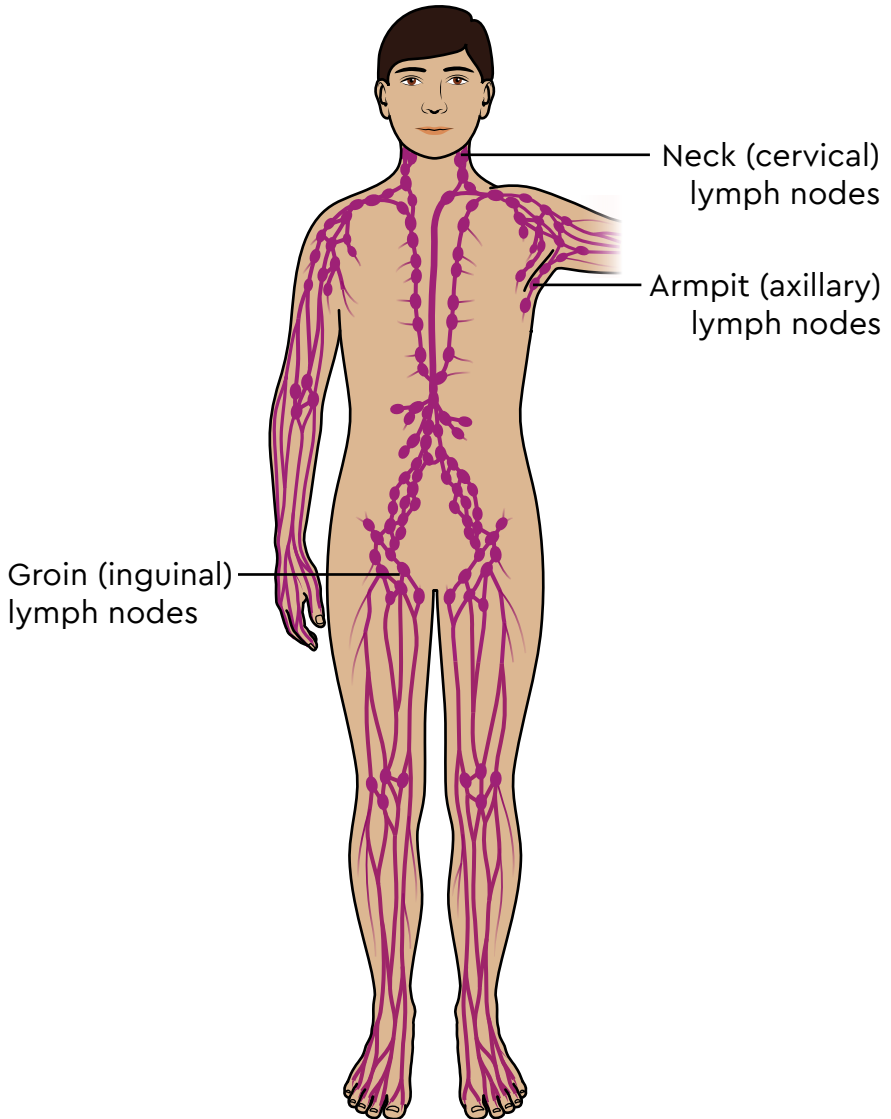
To understand lymphoedema, it helps to know about the lymphatic system.

The lymphatic system is part of the body's immune system. It helps protect us from infection and disease. Lymph fluid passes through lymph nodes. A network of lymph vessels connects the lymph nodes together. You have nodes throughout your body.

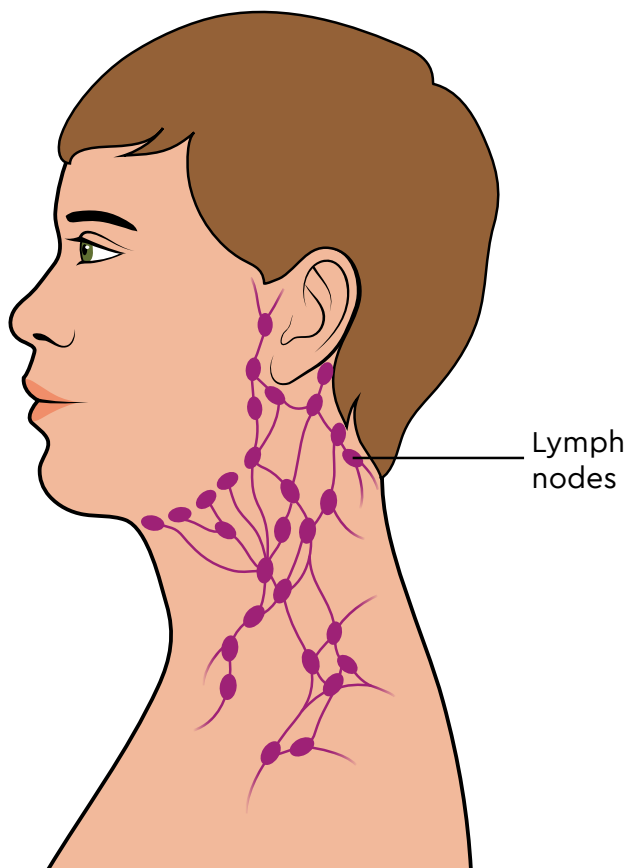
The lymphatic system does different things:

- it acts as a one-way drainage system – this means it moves fluid from body tissues into the blood circulation
- it contains white blood cells called lymphocytes, which fight infection
- it gets rid of any waste that cells make.

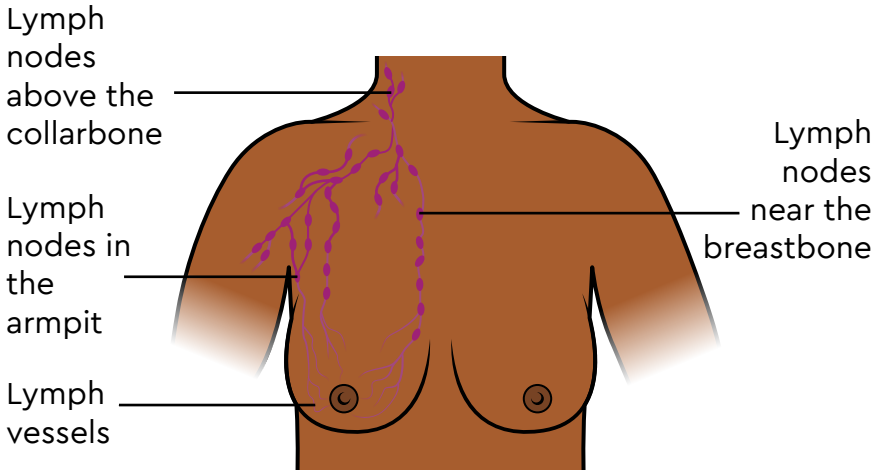
## The lymphatic system



## Head and neck lymphatics



## Breast lymphatics



## Lymph vessels

Lymph vessels are a network of tubes. These tubes connect to groups of lymph nodes throughout the body. Some vessels are just under the skin. This means breaking the skin can easily damage them.

Lymph fluid travels through the lymph vessels and drains into the bloodstream.

## Lymph fluid

This is a colourless fluid that is made in the body. It surrounds all body tissues. Extra fluid from tissue in the body drains into and flows through small lymph vessels. This fluid is filtered through the lymph nodes, and drains back into the bloodstream.

### Lymph nodes

There are lymph nodes throughout your body, but mainly in the neck, armpits, groin and tummy (abdomen). They filter and break down bacteria (germs) or other harmful cells from the lymph fluid. They are sometimes called lymph glands.

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 differs from person to person.

Different parts of the body have different numbers of nodes. For example, there are about 15 to 30 small nodes in the armpit.

### How the lymphatic system works

Lymph fluid normally flows through a network of lymph vessels. These lymph vessels connect to a group of lymph nodes. The nodes act as a filter. They trap or destroy anything harmful that the body does not need. Inside the lymph nodes are white blood cells, also called lymphocytes. These white blood cells attack and break down bacteria, viruses, damaged cells or cancer cells.

The lymph fluid carries the waste products and destroyed bacteria back into the bloodstream. The liver or kidneys then remove these from the blood. The body passes them out with other body waste, through bowel movements (poo) or urine (pee).

Lymph nodes sometimes trap bacteria or viruses that they cannot destroy straight away. For example, they may do this when you have an infection. When the lymph nodes are fighting the infection, they often swell and become sore to touch.

Sometimes, cancer cells spread into the lymph nodes from a cancer somewhere else in the body. This is called secondary cancer in the lymph nodes. Cancer can also start in the lymph nodes themselves. This is called lymphoma. If there is cancer in the lymph nodes, they may swell but are usually painless.

There are different causes of swollen lymph nodes. But if you notice a painless, swollen lymph node, it is important to get it checked by your GP.

**“ I have developed mild lymphoedema as a result of lymph node removal. ”**

Marie, living with lymphoedema

# How lymphoedema develops

Sometimes, lymph nodes or vessels are damaged, blocked or removed. This means it is harder for lymph fluid to drain. The fluid can then build up between the tissues. This can cause swelling.

Sometimes, cancer or its treatment can damage or block lymph nodes or vessels. Once this happens, it is not possible to repair them. A doctor may need to remove the lymph nodes completely during treatment. This means if lymphoedema develops, it cannot be cured. Part of the treatment for lymphoedema is learning things you can do to manage it yourself (page 34).

It is usually possible to reduce the swelling if it is diagnosed and treated early. But it does not go away completely. This is called a chronic condition. Sometimes, if the swelling is small and treatment starts early, the area can return to normal size. You still need to follow advice from your specialist to reduce the risk of the swelling coming back.

There are things you can do to reduce the risk of lymphoedema developing (pages 24 to 29).

# Causes of lymphoedema

Not everyone with lymphoedema has had cancer. But you may develop lymphoedema because of the following:

- **Surgery to remove lymph nodes.** Surgery interrupts the normal flow of the lymphatic system, causing fluid to build up in the affected area. The risk is lower if you only had 1 or 2 lymph nodes removed (sentinel lymph node biopsy) than if you had a group of lymph nodes removed.
- **Radiotherapy to the lymph nodes.** Radiotherapy can cause the tissue in the affected area to harden. This blocks the flow of lymph fluid.
- **Cancer cells spreading to the lymph nodes.** This causes a blockage that leads to a build-up of fluid.
- **Cancer that is pressing on the lymph vessels.** This causes a blockage in the lymph nodes close by, that leads to a build-up of fluid.

Not everyone who has lymph nodes removed, or radiotherapy to the lymph nodes, will get lymphoedema. But there is a risk of developing it.

## Lymphoedema after cancer treatment

Lymphoedema can develop in the following areas:

- **Arm.** This may be after surgery or radiotherapy to the armpit to treat breast cancer or melanoma.
- **Leg.** This is if cancer or its treatment affects the lymph nodes in the pelvis or groin area. This may happen after surgery or radiotherapy for gynaecological cancers (cancer of the womb, cervix, ovary or vulva), anal cancer or prostate cancer. Or it can happen after treatment to the lymph nodes in the groin for melanoma.
- **Breast or chest** after breast cancer treatment.
- **Pelvic area and genitals** after surgery or radiotherapy to lymph nodes in the pelvis. You may have this treatment for cancer of the prostate, bladder, womb, vagina, testicles, penis or rectum.
- **Face, head and neck** after surgery or radiotherapy to lymph nodes in the neck.

If you have surgery, it is common to get swelling (oedema) near the surgery scar in the first few days after the operation. This can take several weeks to go away completely. This type of swelling is not the same as lymphoedema, which usually happens a few months or years later.

If you are worried about any swelling, always talk to your cancer doctor or specialist nurse.

# Signs and symptoms

Lymphoedema can happen anywhere in the body, including the arms, legs, head and neck, chest area and genital area. The symptoms vary depending on how mild, moderate, or severe the lymphoedema is.

To reduce the risk of lymphoedema getting worse, you should ask your cancer doctor or specialist nurse for advice as soon as you notice any of the following:

- **Swelling.** Your clothing, shoes or jewellery (rings or watches) may feel tighter than usual, even before you notice any swelling.
- **Changes in how the limb feels.** The limb (or part of the limb) may feel heavy, tight, full or stiff. If the lymphoedema is severe, the swelling may change the shape of the limb.
- **Skin changes.** Skin in the affected area may feel tight, stretched or a thicker texture. Sometimes it can be dry, flaky, rough or scaly. In later stages, the skin tissue often hardens or becomes more fatty. There may also be more complex skin problems.
- **Aching in the affected area.** You may feel some discomfort or aching where the swelling is.

Swelling, aching and redness in the arms or legs can also be symptoms of a blood clot. It is important to tell your doctor or nurse straight away if you have any of these symptoms. If you cannot speak to your doctor, call the NHS urgent advice number, **111**.

## Other symptoms

Symptoms will vary depending on how much lymphoedema there is, and whether it is mild, moderate or severe. At first you may not notice any swelling. Or gentle pressure may leave an indent on the skin. This is called pitting oedema.

In later stages, the skin tissue often hardens or becomes more fatty. There may also be more complex skin problems (pages 69 to 72). Sometimes, lymph fluid leaks from the skin. This is called lymphorrhoea. It is due to fluid building up in the tissues, or because of damage to the skin.

If the lymphoedema is more severe, it may be difficult to move about and do everyday things. Or it may change the normal shape of the affected limb.

**“ My lymphoedema is localised in my left ankle and leg, meaning my leg swells up throughout the day. ”**

Karen, living with lymphoedema

# Diagnosis

If your cancer doctor, specialist nurse or physiotherapist thinks you have lymphoedema, they should refer you to a lymphoedema specialist. Health professionals with specialist knowledge in treating lymphoedema may include:

- specialist lymphoedema nurses
- breast care nurses
- specialist doctors
- physiotherapists
- occupational therapists.

Organisations such as the Lymphoedema Support Network (LSN) and the British Lymphology Society (page 106) can advise about specialist services near you. The Lymphoedema Support Network also has advice for GPs who are having difficulty referring to a lymphoedema service.

Not all swelling is lymphoedema. Sometimes you need tests to make sure nothing else is causing the swelling, like a blood clot. You may have scans to see whether the lymphoedema is caused by a cancer affecting the lymph nodes.

## Your lymphoedema specialist

Your lymphoedema specialist will confirm the diagnosis and assess how much the lymphoedema is affecting you.

Your specialist will:

- ask about your medical history
- check your skin and look for any changes
- assess the size and shape of the area
- assess how the tissue feels under the skin
- measure your limb and compare it to the unaffected limb
- check your movement and ability to do everyday things.

If it is difficult to diagnose lymphoedema, you may have other tests. Your cancer doctor or specialist nurse will talk to you about what tests you might need depending on your symptoms.

Your lymphoedema specialist should always do a full assessment. This is so they can decide the best way to manage and treat the lymphoedema.

Part of the treatment for lymphoedema is learning things you can do to manage it yourself.





# Reducing your risk of lymphoedema

Ways to reduce your risk

24

# Ways to reduce your risk

We do not know why some people develop lymphoedema and others do not. But following the advice in this section may help to reduce your risk of lymphoedema.

Anyone who has had surgery or radiotherapy that affects their lymph nodes (pages 8 to 9) is at risk of developing lymphoedema. The risk is greater if:

- the lymph nodes in the armpit, groin or neck are affected
- you have had both surgery and radiotherapy to the lymph nodes
- you are overweight.

You may have had just 1 or 2 lymph nodes removed. This is called a sentinel lymph node biopsy (SLNB). Or your doctors may have removed a complete group of nodes. This is called lymph node clearance. Having a complete group of lymph nodes removed increases the risk of lymphoedema. If you have had an SLNB, you are still at risk of getting lymphoedema, but the risk is lower.

Being overweight or having a skin infection called cellulitis may cause swelling in someone who is at risk of developing lymphoedema. Or it may be that some people's lymphatic systems do not work as well as others.

If an area becomes inflamed or infected, the body makes extra fluid. If this area of your lymphatic system is not working properly, the build-up of fluid could cause lymphoedema. Fatty tissue that blocks the lymph nodes can also stop the lymphatic system from working properly.

Following the advice in this section may help to reduce your risk of lymphoedema.

## Look after your skin

It is important to keep the area at risk of lymphoedema clean. You should also moisturise it well. This reduces the risk of the area becoming inflamed, infected or dry. It is also important to protect your skin from cuts, grazes, insect bites and sunburn. It can help to use gloves for household tasks such as cleaning or gardening. This can help prevent the skin from breaking.

We have more detailed information about looking after your skin (pages 35 to 38).

## Prevent pressure on the area

You may be advised to avoid pressure on the area. This is because it can affect the flow of lymph fluid (pages 8 to 9). This depends on which part of the body is at risk.

If possible, you should avoid:

- having your blood pressure taken from the arm at risk
- having needles in the arm at risk – for example having injections or blood samples taken
- wearing tight jewellery such as rings, watches, bracelets, ankle bracelets or toe rings
- wearing tight clothing such as tight armholes, waist bands, or bra straps.



## Watch for early signs of infection

It is important to be aware of early signs of a skin infection called cellulitis in the area at risk of lymphoedema. Doctors can then treat the infection straight away with antibiotics. Contact your GP straight away if you notice flu-like symptoms, or any of the following signs:

- redness or warmth in the area at risk
- a new, painful swelling in the area at risk
- pain or tenderness in the area at risk
- red streaks that go up or down from the area at risk
- a high temperature or fever.

## Try to exercise and keep active

Muscle activity helps improve the flow of lymph fluid in the body. Doing regular exercise and keeping active encourages the fluid to drain. It also helps with joint movement.

Gentle stretching exercises can help your arm or leg return to normal after surgery or radiotherapy. You should do exercises gently and start gradually. A physiotherapist will usually show you what exercises to do. It is important you do them for as long as they advise after surgery. This will help you recover.

After your treatment finishes, you can usually get back to any physical activity or exercise you did before. Or you may decide to do something new. It is important to start slowly and gradually increase the intensity. You may need to be more careful with certain types of exercises. These include lifting heavy weights, or playing physical contact sports. This is because they are more likely to injure the skin or muscles in the area at risk of lymphoedema. These sports may be fine if you have always done them, but check with your GP or lymphoedema specialist first.

Physical activity will help you to:

- feel better generally
- maintain your weight
- breathe more deeply, which helps lymph fluid flow.

Breathing exercises on their own, or as part of yoga or pilates, can also help (page 59). Ask your physiotherapist or specialist nurse for advice about exercise.

## Keep to a healthy weight

The risk of getting lymphoedema increases if you are overweight. It is important to try to keep your weight within the normal range for your height. Your GP or practice nurse can tell you your ideal weight for your height. You can also ask them, or a dietitian, for advice and support on healthy eating.

We have more information about keeping to a healthy weight when you have lymphoedema (pages 77 to 78).

We also have general information about healthy eating and weight management. You may find our booklet **Healthy eating and cancer** useful (page 100).

## Take care when travelling

Here are some tips to help reduce your risk of developing lymphoedema when travelling:

- Avoid sitting in the same position for the whole journey.
- Move around often, and do gentle stretching exercises if you are on a plane or train.
- During long car journeys, make regular stops to get out and walk around.
- Wear comfortable clothes and shoes, and avoid tight-fitting clothes.
- Use a suitcase on wheels that you can pull, to avoid extra strain on your muscles.

Even if you do not have lymphoedema, you may need to wear travelling socks during a long flight, to prevent a clot in your legs. Talk to your doctor or pharmacist for advice.



# Treating lymphoedema

Managing lymphoedema	32
Skin care	35
Exercise and keeping active	40
Positioning and moving the area affected by lymphoedema	44
Compression treatment	46
Lymphatic drainage	55
Deep breathing exercises	59
Lymphoedema in areas that are difficult to treat	61

# Managing lymphoedema

Management of lymphoedema aims to:

- reduce and control swelling
- help with discomfort
- stop fluid build-up.

It should make the affected area less swollen, easier to move and feel more comfortable. Sometimes, it may take several weeks or months before you notice much improvement.

Your lymphoedema specialist will talk to you about the best way to manage your situation. You will usually have a combination of treatments, as they work better when used together.

The main ways to manage lymphoedema are:

- skin care
- exercises and keeping active
- positioning of the limb or area
- compression
- a type of massage called lymphatic drainage.

You may have other treatments, including taping and surgery. But these are less common.

These treatments usually help reduce lymphoedema, wherever it is in the body. Your lymphoedema specialist will explain the best way of managing lymphoedema in areas of the body that are more difficult to treat. This includes the breast or chest, head and neck area, and the genitals.

To start with, you may have regular treatment from your lymphoedema specialist. After this, the specialist will talk to you about how you can manage the lymphoedema yourself (page 34).

## Avoiding pressure on the area

Your lymphoedema specialist will also advise you to avoid pressure on the area. This is because it can affect the flow of lymph fluid. This depends on which part of the body is affected.

If possible, you should avoid the following:

- Having your blood pressure taken in the affected arm, unless it is an emergency. If you have lymphoedema in both arms you can switch between the left and right arm each time.
- Wearing tight jewellery such as rings, watches, bracelets, ankle bracelets or toe rings.
- Wearing tight clothing such as tight armholes, tight waist bands or tight bra straps.

You should try to find a well-fitting bra with a wide shoulder strap and deep sides. This can help give support and make you feel more comfortable.

You should also avoid having needles in the affected arm when possible, for example having injections or blood samples taken. This can help avoid infection from areas of broken skin.

## Self-managing lymphoedema

Learning how to manage lymphoedema yourself is the main part of treatment. This means you have fewer hospital appointments. It also gives you more control over when to do your lymphoedema treatment, so you can fit it into daily life.

After your lymphoedema specialist has assessed you, they will discuss the best way to manage the lymphoedema. You will usually have a combination of treatments.

You need to do the treatments regularly to get the best results. Your specialist will tell you how often to do them. You can slowly add your lymphoedema care into your daily routine.

Family or friends often want to help, and there may be practical things they can do. They may be able to help with tasks you find difficult because of the swelling. They could also help you with your compression garment or give you a simple lymphatic drainage massage (pages 57 to 58).

# Skin care

It is important to look after and protect your skin to avoid injury or infection. If you have lymphoedema or are at risk of it, you are also at risk of a skin infection called cellulitis (pages 69 to 71). It is important to know the signs of an infection. Good skin care can help reduce the risk of cellulitis.

## Keeping your skin in good condition

Lymphoedema can make your skin dry and itchy. This makes cracks and breaks in the skin more likely and increases your risk of infection. You can help keep your skin in good condition by doing the following:

- **Moisturising every day** – if your skin is in good condition, you can use any moisturiser. If you have dry skin or other skin problems, your lymphoedema specialist can suggest the best creams for you. You can buy moisturising creams from your local pharmacist. You can also get some on prescription from your doctor. When you put on moisturiser, make sure the last stroke is downwards (in the direction of hair growth). This stops the moisturiser blocking hair follicles (folliculitis).
- **Keeping your skin clean** – wash with warm water every day. If you have dry skin, use soap-free cleansers.
- **Carefully drying the area after washing** – if the lymphoedema is in a limb, make sure you dry in between fingers or toes of the affected limb.
- **Keeping your feet dry** – if lymphoedema affects your feet, make sure you dry between your toes to help prevent athlete's foot (a fungal infection). You can use anti-fungal powder to treat the symptoms of athlete's foot – such as peeling or itchy skin.

## Avoiding cuts and grazes

You are more likely to get an infection if your skin is broken. It is impossible to avoid all skin injuries. But there are things you can do to reduce the risk:

- **Protect your skin** – wear long sleeves, gloves or long trousers when doing tasks that may increase the risk of cuts and scratches. For example, you should wear these when doing household cleaning, DIY, gardening or cooking.
- **Take care around pets that might scratch** – try to keep them away from the affected area. Or think about clothing or blankets that could protect you.
- **Be careful removing unwanted hair that is in, or near, the affected area** – an electric shaver is the safest way to remove hair. Razor blades, waxing and sugaring can all damage the skin. Some people use hair removal creams, but these can be harsh on the skin. If you use these, always test a small area first.
- **Use nail clippers instead of scissors to cut your nails** – you are less likely to cut the skin using these. It is also best not to push back or cut your cuticles. Tell your doctor or lymphoedema specialist if you need extra help with your toenails. They can refer you to a foot specialist (chiropodist). Tell the chiropodist that you have lymphoedema, or that you are at risk of it.
- **Wear shoes that fit well, protect your feet and do not rub** – if you have lymphoedema in the leg, it is safest not to walk around barefoot. This is in case you step on something or stub your toe.
- **Do regular exercise** – exercise (pages 40 to 43) can help improve the symptoms of lymphoedema. But some sports can increase your risk of damaging the skin. Your specialist can talk to you about any care you should take for a specific sport.

## Avoiding bites and burns

### Insect bites

Using a good insect repellent can help to prevent insect bites. Your pharmacist can give you advice about the best one to get. Look for a repellent with at least 50% DEET. DEET is the active ingredient in insect repellent.

### Sunburn

Sunburn can cause dryness and blistering. Try to wear clothes that cover you in the sun. Make sure you use suncream with a sun protection factor (SPF) 50. Sunbeds or sun lamps are not recommended because of the risk of skin cancer.

## If you get a cut, graze, burn or bite

If you do get a cut, graze or burn, treat it as soon as you can, even if it is only small:

- wash and dry the area thoroughly
- put antiseptic cream on it
- cover if necessary.

If you get an insect bite or sting that is on or near the affected area, try not to scratch it. Scratching may cause more damage to the skin. Using antihistamine cream may help reduce itching. Speak to your GP for advice if the broken skin does not heal or shows any sign of infection.

## Avoiding skin damage

### Injections and vaccinations

When seeing any healthcare professional, always tell them about your lymphoedema. This is so they can try to avoid putting any needles into the affected area. This could be for injections, vaccinations or a drip (infusion). This is a precaution to reduce the risk of infection. However, they may need to do this if it is a medical emergency.

### Lymphoedema alert bracelet

It may be helpful to wear a lymphoedema alert bracelet. This will remind healthcare professionals that they should not use the affected arm for needles. These are available from the Lymphoedema Support Network (LSN) – page 106.

### Tattoos and acupuncture

If you have lymphoedema, it is best to avoid tattoos or acupuncture on the affected area. Talk to your doctor or nurse before having either of these on other areas of your body.

## Avoiding extreme temperatures

Extreme temperatures, like being too hot or too cold, can sometimes make swelling worse. Here are some tips for avoiding this:

- Be careful using saunas, hot tubs and steam rooms. Only spend short amounts of time in them until you can be sure that swelling does not get worse.
- Try not to sit too close to a fire or other heat source.
- Always test the temperature of the water before you have a bath or shower, to avoid burning yourself.



# Exercise and keeping active

Physical activity is important for managing lymphoedema, because it:

- works your muscles, which increases the flow of lymph fluid (pages 8 to 9) and helps move it away from the swollen area
- can help you maintain a healthy weight, which can reduce lymphoedema swelling
- keeps your joints flexible, maintaining and improving your range of movement.

Physical activity can also help you feel better about yourself and reduce stress and anxiety.

You can use your affected limb for all your normal activities, but take care with anything that might cause muscle strain. You may have to wait until the swelling improves to do some activities.

## Keeping physically active

If you have not been active for a while, it is best to start slowly and build up. The most important thing is to do it regularly.

It is important to remember that swelling may increase if you exercise too quickly, too often or for long periods of time. Your skin may become red, sticky and hot. If this happens, you should stop and rest. You should not exercise if you have a skin infection (cellulitis). There is more information about cellulitis on pages 69 to 71.

You should ask your lymphoedema specialist for advice if:

- you become more breathless
- you become more uncomfortable than expected during exercise
- swelling gets worse – if this happens, stop straight away.

We have more information in our booklet **Physical activity and cancer** (page 100).

Your lymphoedema specialist will explain some gentle exercises that are best for you. They will also tell you how many times a day you should do them.

**“After treatment I was weak, but found I could do gardening from a deckchair. Gradually I started doing more without noticing because I was so absorbed in what I was doing. Gardening can be as gentle or strenuous as your body can cope with so there is always something that you can do. ”**

Anne, living with lymphoedema

## Exercises to reduce arm swelling

Here are some simple exercises to reduce arm swelling:

1. Sit comfortably and support your arm at shoulder height – you could use pillows. Make a fist and then stretch your fingers out straight. Repeat this exercise as many times as feels comfortable.
2. With your arm supported by a cushion or pillow, try bending and straightening it at the elbow.
3. Check that your shoulders are level by looking at your posture in the mirror. Practise shrugging, and then dropping your shoulders slowly. Count to 5 as you do this.
4. Slowly circle your shoulders together forwards, then backwards.

## Exercises to reduce leg swelling

Do the following exercises regularly while you are sitting down:

1. Put your leg in front of you, and rest it on something so it is supported behind the knee.
2. Move your foot at the ankle to pull your toes up and then point them down.
3. Slowly bend and straighten your leg at the knee.

What is right for you will depend on your fitness level. Your lymphoedema specialist can suggest other exercises that might help.

Lymphoedema Network Northern Ireland produces 2 leaflets with exercises for arms and legs. You can find their details on page 106.

UK NHS Lymphoedema Network Wales has created a number of videos that explain different levels of exercises you can do:

**[vimeo.com/ehdm/ilf-lymphodema-18](https://vimeo.com/ehdm/ilf-lymphodema-18)**

## Types of physical activity

The type of activity you do could be gentle stretches, or something that you enjoyed before.

There may be some types of physical activity that you will need to take more care with. You may need to be careful if there is a high risk of muscle strain or skin injury. Always ask your lymphoedema specialist for advice and talk to your doctor before you start.

Some good types of exercise include:

- Swimming
- walking
- stretching
- yoga.

Swimming and aqua aerobics are helpful if you have problems with your joints, as they put less strain on them.

## Compression garments and physical activity

If you have a compression garment (pages 46 to 53), you usually need to wear it when you exercise. Speak to your specialist if you find this uncomfortable. Try to include deep breathing (page 59) in any daily exercise routines, as this improves your circulation.

# Positioning and moving the area affected by lymphoedema

There are ways you can position your limb when resting that can prevent fluid from building up.

Careful positioning when resting or sitting can reduce swelling for lymphoedema in an arm, a leg, or the head and neck.

## If you have arm swelling

- Place a cushion on the arm of a chair. Rest your arm on this when sitting down – this will fully support your arm and raise it slightly.
- Try not to lift your arm above shoulder height for too long – it may reduce blood flow to your arm and make you more uncomfortable.
- Try not to leave your arm in the same position for too long – it is more helpful to move muscles regularly.

## If you have leg swelling

- Sit with your legs uncrossed.
- Raise your legs as often as you can when you are sitting. Lie with your legs up on a sofa, or fully supported on a footstool.
- Try not to keep your leg in the same position for too long.
- Get up and move about at least once an hour, if you can.
- Avoid standing still for long periods of time.

If you have to stand for a long time, these exercises can help stop fluid building up:

1. Raise yourself up onto your toes and lower back down again. This helps tense and relax your calf muscles.
2. Shift your weight from one leg to the other. Transfer your weight from your heels to your toes, as if you are walking on the spot.
3. Try rocking back on your heels and forward onto your toes a few times.

## **If you have head and neck swelling**

It can help lymph fluid to drain if you slightly raise your head and upper body while you sleep. You can do this by:

- raising the head of the bed slightly – for example by using blocks under the legs of the bed
- using a foam wedge under your upper body and head
- using pillows.

Try to keep your head in line with your body, so your neck is not bent too far forward. This will help fluid to drain.

# Compression treatment

Compression can be an essential part of lymphoedema treatment. This could be given using compression garments, bandages or pumps.

## Compression garments

Compression can help reduce and control lymphoedema. It does this by limiting lymph fluid build-up and helping the fluid move to an area that is draining well. It helps muscles pump fluid away.

Compression garments are available in different levels or grades of pressure. The garment you have will depend on how much swelling there is, and which part of the body it affects.

Your lymphoedema specialist may prescribe and fit you with a compression garment. Your GP can also prescribe garments, but usually only on the advice of your lymphoedema specialist.

## Types of compression garment

Depending where the swelling is, you may be fitted with:

- sleeves for swollen arms
- stockings for swollen legs
- garments for lymphoedema in the fingers or toes
- a compression bra or vest for lymphoedema around the breast or chest area
- garments for lymphoedema that affects the genital areas
- compression wraps, which are a system of Velcro™ straps that fit together.

## Having a compression garment fitted

It is important that someone who is experienced in measuring and fitting compression garments fits your garment. Your lymphoedema specialist will usually do this or arrange it for you.

Compression garments are available in different levels or grades of pressure. What is right for you depends on how much swelling you have. They come in different colours, such as beige, brown or black. There are also hypo-allergenic products for people with sensitive skin. There may be a ready-made garment to match your exact measurements. Or your lymphoedema specialist may need to order a garment to be specially made for you.

Your GP can prescribe garments, but usually only on the advice of your lymphoedema specialist. Your specialist will discuss the best garment for you and choose the correct size. They will then ask your GP to get the garment for you.

### Compression garments for your torso

A compression garment should not dig into the chest, back or shoulders. If you have lymphoedema around the chest area, a compression bra, vest, or sports bra might help. Your lymphoedema specialist can tell you whether this would help in your situation.

If you have genital oedema your specialist can advise you and may provide specific garments that might help. These could be lymphoedema compression garments or well-fitting sportswear.

### Compression toe caps and gloves

If you have lymphoedema in your fingers or toes, you may need compression toe caps or gloves for these areas. You may also need a garment for your arm or leg.

## Putting on and removing compression garments

When you are fitted for your compression garment, you will be shown how to put it on and take it off.

For arm sleeves:

1. Fold the top down to the elbow or until the garment is in half, before you put it on.
2. Slowly pull the sleeve up your arm using your other hand.

It may help to hold onto something fixed while you do these steps. For example, you could hold on to a locked door handle.

For leg garments, it may help to fold the stocking down to the ankle or heel part then slowly pull it on.

Here are some more tips for putting on and removing compression garments:

- Put your garment on first thing in the morning, when the limb is at its smallest. It is best to wait a short while after a shower or bath. If your skin is damp, it can be difficult to put on.
- Pull the garment over your hand or foot and ease it up, a bit at a time. Make sure you do not pull it up by the top of the garment.
- While you are wearing the garment, do not turn or roll the top over. This will restrict the blood flow and cause more swelling.

- Using a little unperfumed talc on your arm or leg can help ease the garment on. There are other things available to help garments on and off. Your lymphoedema specialist can tell you where to buy these.
- Make sure the material is spread evenly and there are no creases when your garment is on. Wearing a rubber glove can help you put the garment on and smooth out any creases.
- Moisturise your skin at night after you take off your garment. It can help to avoid creams just before putting on your garment as they might make it more difficult to put on.



## When not to use compression garments

There are some situations when you should not wear compression garments. Always follow advice from your lymphoedema specialist, but you should usually avoid wearing one if:

- the skin is fragile or damaged
- the skin is pitted, folded or leaking lymph fluid
- you have cellulitis (pages 69 to 71) or pain in the area.

Using compression garments incorrectly can harm you. It also means they will not help the swelling reduce. The material can form tight bands across the skin and even damage it. If you are unsure, ask your lymphoedema specialist for advice.

If you have been fitted with a garment and you notice a change in sensation, the garment may be too tight. Signs of this can be:

- numbness
- pins and needles
- pain
- your fingers or toes changing colour.

If you have any of these, remove the garment straight away and contact your lymphoedema specialist for advice. It is important that you are properly measured and fitted to prevent this happening.

**“ I developed lymphoedema in my right arm. I sustained a tiny blister, which allowed infection to set in, resulting in swelling. I am extremely careful now in looking after my hand and arm. I sometimes have to wear a ‘sleeve’ – but it doesn’t interfere with my day-to-day activities. ”**

Naomi, living with lymphoedema

## Questions about compression garments

### **When should I wear my compression garment?**

It is important to wear your compression garment all day. You can usually take it off at night, or when you are lying down and resting. If you are finding it too much, ask your specialist about taking breaks from it.

### **What if my compression garment feels uncomfortable?**

If the garment feels very uncomfortable at first, you could try only wearing it when you are most active. In time you should find it more comfortable, and can increase the amount of time you wear it for. However, if you still are finding it difficult to wear, ask your lymphoedema specialist to check it fits correctly.

### **How many compression garments will I get?**

You will get at least 2 garments, so you can have 1 in the wash while you wear the other. Follow the washing instructions on the garment. The garments usually last longer if you wash them by hand rather than in a washing machine.

### **How long should each compression garment last?**

Each garment should last 3 to 6 months, if you are wearing them every day. So your 2 garments usually last 6 to 12 months before they need replacing. Your lymphoedema specialist will need to measure you again before you get replacements.

## **What if I lose or gain weight?**

If your weight changes, your lymphoedema specialist will need to measure you again for a new garment. If your compression garment is too loose, it will not control swelling. If it is too tight, it will restrict blood flow.

## **Do I need to wear the garment in hot weather?**

It is often uncomfortable to wear garments in hot weather. Some manufacturers produce cotton-rich garments. These can be helpful in the summer months, and also for people who have skin allergies. You can cool down your garments by putting the spare one in a plastic bag in the fridge (not freezer).

It can also help to spray cool water over the garment while wearing it. If wearing the garment in hot weather is still too uncomfortable, talk to your lymphoedema specialist. They may have other suggestions to help you.

## **Do I need to wear the garment when travelling for a long time?**

When travelling a long way (pages 81 to 83), especially by plane, make sure you wear your compression garment. You need to do this a few hours before your journey, during the whole journey itself and for some hours afterwards.

## **Lymphoedema compression bandages, wraps and pumps**

Rarely, your arm or leg can get very swollen or change a lot in shape, making it difficult to fit a compression garment. Or your skin may become fragile from putting on and removing it.

To reduce the swelling and improve the shape, you may have special multi-layer compression bandages with padding. A lymphoedema specialist will usually put the bandages on every 1 to 2 days. After a few weeks of bandaging, it may be possible to fit a compression sleeve or stocking.

Lymphoedema wraps are a system of Velcro® straps that fit together. They can be used instead of compression garments, or at the same time. Your specialist will discuss whether a wrap compression system may be more suitable for you.

Sometimes, your lymphoedema specialist may ask you to use a compression pump to treat lymphoedema in a limb. When you turn the pump on, the sleeve or leg garment slowly inflates and deflates. You can do this at home and your lymphoedema specialist can give you more information.

Before using the pump, it is important to drain lymph fluid from these areas using lymphatic drainage (pages 55 to 58).

# Lymphatic drainage

Lymphatic drainage is a specialised, gentle type of medical massage. It may be used as part of your lymphoedema treatment. The aim is to encourage the lymph fluid to move away from the swollen area, so it can drain normally. It also helps lymph fluid drain through the healthy lymph vessels. This helps control swelling.

There are 2 main types of lymphatic drainage:

- manual lymphatic drainage (MLD)
- simple lymphatic drainage (SLD).

You should only have MLD from a trained lymphatic drainage therapist. It is a short course of treatment.

SLD is something you can be shown how to do yourself. You can continue with this long term.

You should not have other types of massage on the affected area.

## Manual lymphatic drainage (MLD)

There are several different techniques for MLD. They are all similar but use different massage movements. Your therapist can tell you more about the method they use and what it involves. Breathing techniques (page 59) are also an important part of MLD.

You usually have MLD along with compression garments or bandaging (pages 46 to 54) to keep the swelling down. But MLD can be particularly useful in areas where it is difficult to use compression therapy. For example, MLD can be used if you have head and neck or genital lymphoedema.

NHS lymphoedema treatment clinics often give short courses of MLD. However, it is not available at all centres. If you have difficulty finding a qualified MLD therapist, contact Manual Lymphatic Drainage UK (page 107). Or the British Lymphology Society (page 106) has a directory on its website that you may find helpful.

### **Having MLD**

Your therapist will tell you how often you will have MLD. The length of the course may vary, and it is sometimes combined with other treatments. Before and after MLD, your therapist will do some breathing exercises with you.

You will usually lie down. You may need to remove some of your clothing. Your therapist will begin by treating unaffected lymph nodes. This frees up space for fluid from the affected area to drain into. They will use some pressure and slow, regular movements. Your therapist may ask you to do some simple movements during the treatment to help the lymph to drain.

To help keep the swelling down between treatments, your therapist will show you how to do a simple version of MLD yourself at home. It is a type of self-massage called simple lymphatic drainage (SLD).

You will not have MLD if you have an infection called cellulitis in the swollen area. You also cannot have it if you have certain medical conditions, such as heart problems.

## Simple lymphatic drainage (SLD)

Your lymphoedema specialist may suggest simple lymphatic drainage (SLD) as part of your lymphoedema treatment. This is a simplified version of manual lymphatic drainage (MLD). It is sometimes called self-lymphatic drainage.

It is important that you learn these techniques from a lymphoedema specialist before you start. They will show you how to massage the area where you do not have lymphoedema. This helps to make some space for the fluid to drain into from the swollen area. They can also show a friend or family member how to do it.

Usually, you do not massage the swollen area.

### Doing SLD

Your lymphoedema specialist will explain how to do the massage and show you the right amount of pressure to use. This will depend on your situation.

The aim of this massage is to improve the flow of lymph fluid in the healthy lymph vessels. Once the vessels have cleared, the excess fluid from the swollen area can drain away more easily.

It is best to choose a time and a place where you can do SLD in a relaxed way. This could be somewhere nothing will interrupt or distract you. Make sure you have everything you need before you start, and get into a comfortable position. Remember to do your deep breathing exercises first.

You do not use any oils or creams for the massage. You use your hand to very gently move the skin in a particular direction. You always move the skin in the direction away from the swelling. You could use a little talcum powder if your skin is sticky. If your skin is red when you have finished, then the movement is too much.

The Lymphoedema Support Network (page 106) has information on the self-management of lymphoedema and SLD.

## Hand-held massagers

Hand-held massagers may be useful for people who have less movement in their hands. Some people find it helpful to use a soft baby brush or shower puff as a massager. You should talk to your lymphoedema specialist before buying any hand-held massagers.

**“ I have lymphoedema treatment and massage for the build-up of lymphatic fluid that has difficulty draining away on the left side of my body. ”**

Caroline, living with lymphoedema

# Deep breathing exercises

Before and after manual lymphatic drainage (MLD) and simple lymphatic drainage (SLD) massage, breathing exercises can help lymphatic drainage. Use the following simple exercise:

Sit upright in a comfortable chair or lie on your bed with your knees slightly bent.

1. Rest your hands on your ribs.
2. Take slow, deep breaths to relax.
3. As you breathe in, move the air down to your tummy (abdomen). You will feel your tummy rising under your hands.
4. Breathe out slowly by sighing the air out. While breathing out, let your abdomen relax inwards again.
5. Do the deep breathing exercise 5 times.
6. Have a short rest before getting up, to avoid feeling dizzy.

You can contact our cancer support specialists on **0808 808 00 00** for more information.



# Lymphoedema in areas that are difficult to treat

Lymphoedema is most common in an arm or a leg. But it can affect different parts of the body. This depends on which lymph nodes have been removed or affected.

As with treatment for arm or leg lymphoedema, good skin care is important (pages 35 to 38). Exercising (pages 40 to 43), keeping to a healthy weight (pages 77 to 78) and taking good care of yourself are also important. Your specialist will explain the best way of managing and treating lymphoedema in other parts of your body.

## Breast or chest lymphoedema

### Clothing, bras and prostheses

Clothes that are too tight can stop lymph fluid draining. These can include bras, vests, or anything with a tight waistband.

You should make sure your bra is not too tight around the chest. The straps should not dig into your shoulders or under the arm. Try wearing a bra that has wide and flexible shoulder straps and bands around the chest. It is also important to make sure you have the right cup size. Your lymphoedema specialist can advise you on getting measured correctly.

Some breast prostheses are very heavy. This can cause pressure to the chest area, making bra shoulder straps dig in. If you need to wear a prosthesis, try to get a lightweight one. Your lymphoedema specialist or breast care nurse can advise you about bras and breast prostheses.

## **Compression bras and vests**

If you have breast or chest lymphoedema, your specialist can give you compression bras and specialist vests. You often need to have these made specially for you, so that they fit properly. It can also be helpful to wear a sports bra.

You may need to wear a compression sleeve. This is to stop fluid moving from one area to another. It can also help improve drainage. You do not often have compression bandaging to treat lymphoedema in the breast or chest area.

## **Lymphatic drainage (MLD and SLD)**

You may have manual lymphatic drainage (MLD) and simple lymphatic drainage (SLD) – pages 55 to 58 – to treat breast and chest lymphoedema.

Your lymphatic drainage therapist can give you more information about this.

## Genital lymphoedema

It is important to look after your skin and keep it clean. Skin infections can be more common in the genital area. Genital lymphoedema is usually treated with MLD or SLD (pages 55 to 58).

You may have specially made compression garments (pages 46 to 54). These can be padded to protect swollen areas. Sports clothing or shapewear underwear containing Lycra® may also help. This will depend on how much swelling there is.

Pelvic floor and tummy (abdominal) exercises, combined with deep breathing exercises can help reduce swelling. Your lymphoedema specialist can show you how to do these.

If you have swelling in the scrotum, your specialist may give you a scrotal support. They may use bandaging if the penis is swollen.

Your specialist can tell you more about what might be helpful in your situation. Occasionally, you may have surgery to treat genital lymphoedema. Your doctor will discuss this with you.

## Head and neck lymphoedema

You can usually manage lymphoedema of the face, neck or head with MLD and SLD. Sometimes, you can have Kinesio® taping. You may have special low-pressure compression garments to use in this area of the body. But you should never have compression to the neck area. You sometimes have surgery to treat lymphoedema of the eyelids.



# Other ways of treating lymphoedema

Other treatments	66
Managing problems caused by lymphoedema	69

## Other treatments

Sometimes, you may have other treatments alongside skin care, keeping active, positioning of the limb or area, compression and lymphatic drainage.

Some of the following treatments are new, and more research is needed to find out how well they treat lymphoedema. Your lymphoedema specialist will know how helpful these treatments might be for you and where you can have them.

### Lymphoedema taping (Kinesio® taping)

This is a special taping technique that is mainly used to treat sports injuries. It is also sometimes used to treat lymphoedema.

The tape is made of an elastic cotton material. When the tape is stretched and stuck onto the skin, it gently lifts the top layer of skin. This allows the lymph fluid closest to the surface of the skin to flow more easily. The tape is water resistant, and you can wear it for several days at a time. You usually have this to treat areas where it is difficult to use compression.

The tape is not available on prescription, so you will need to buy it yourself. Your lymphoedema specialist can tell you whether this might be helpful in your situation. They can tell you where to buy the tape from, and advise you on how to use it.

## Surgery

You may have surgery for lymphoedema, but it is rare. You may have it to reduce swelling around the face or genital areas. Or you may have surgery to reduce the size of an affected limb. Surgeons will do this by removing the skin and some tissue underneath.

Doctors may also use specialised surgical techniques to move lymph nodes from one area to another. Or they can move lymph vessels, so that they drain into other lymph vessels or nearby veins. This helps to drain the affected area. These are new treatments in the UK and are not widely available.

You may be able to have liposuction to treat lymphoedema in limbs. Liposuction is when a surgeon makes a number of small cuts in the skin. They then remove swollen, fatty tissue through these cuts using a vacuum. After the operation, you have a compression bandage. You should also keep the limb raised for a few days. About 2 weeks after the operation, a lymphoedema specialist or nurse will remove your bandages. They will give you a compression garment that you need to wear long term. This is to reduce the risk of the swelling returning.

## Laser therapy

This treatment uses a laser to target cells in the lymphatic system. It aims to improve the flow of lymph fluid, soften hard tissue, reduce swelling and stop any swelling from getting worse. Research is happening to find out more about its possible benefits. At the moment, it is not widely available.



# Managing problems caused by lymphoedema

## Infection (cellulitis)

It is important to know the signs of an infection. An infection in the skin is called cellulitis. Getting treatment for an infection as soon as possible puts less stress on the lymphatic system. This can stop lymphoedema getting worse.

If you get cellulitis, the area may become:

- red and hot
- painful
- more swollen.

You may also:

- have red streaks going up or down from the infected area
- have a high temperature (fever)
- feel generally unwell, like you are getting the flu.

If you have any of these signs, contact your GP straight away. They will usually prescribe a course of antibiotics, which you should start straight away. If it happens in the evening or over the weekend, call the NHS urgent advice number on **111**. Do not wait until you can make an appointment with your GP.

You should also contact your lymphoedema specialist. They will usually tell you to stop all lymphoedema treatment until the infection is treated.

Some people with lymphoedema get fungal infections in areas where there are skin folds. For example, your groin, in between the toes, underneath the breasts or any area where you sweat a lot. If you think you have a fungal infection, contact your GP.

Do not wear any compression garments if you have a skin infection and it is painful. Contact your lymphoedema specialist for advice. Rest the swollen area in a comfortable position. For example, you could support the whole limb with a pillow. You should not exercise until the infection has gone.

You should wear your compression garment again as soon as you start feeling better and it is comfortable. You should wear it even if you are taking antibiotics.

### **Managing infection**

In the UK, there is guidance for healthcare professionals on using antibiotics to treat cellulitis when you have lymphoedema. The guidance is written by a group of lymphoedema specialists. It is important your GP follows this guidance when prescribing antibiotics for lymphoedema.

The guidance is available from the British Lymphology Society (page 106).

It is also important to rest, and keep the affected area raised. You should remove compression garments if they are painful. You should not wear them until it is comfortable again. You may need pain relief from your doctor.

Some people with cellulitis need to go to hospital to have antibiotics as a drip (infusion) into a vein. This is called intravenous treatment. This normally happens when cellulitis is more severe, or becomes worse after taking antibiotics at home.

## **Treating lymph fluid leaking from the skin (lymphorrhoea)**

Lymphorrhoea is when lymph fluid leaks from the skin in the affected area. It is not common, but can happen when:

- an area is very swollen
- the skin is very dry
- the area of swelling is difficult to treat, for example the genital area
- there is a break in the skin
- a blister filled with lymph fluid appears on the surface of the skin and breaks.

It is important to take good care of your skin. If you have lymphorrhoea, keep the area clean. The broken skin can easily cause an infection, such as cellulitis.

You should see a lymphoedema specialist as soon as possible if you have lymphorrhoea. They will try to stop the skin from leaking. If you cannot speak to your lymphoedema specialist, contact your GP or district nurse.

The specialist can show you ways of managing lymphorrhoea at home. It may also help you to have some light bandaging. This can reduce swelling in an area that is difficult to manage with a compression garment.

Here are some things you can do while waiting to see a specialist:

- Keep the skin clean and look for signs of infection.
- Apply moisturiser around the area that is leaking.
- Lift your limb when you can – for example, raise an arm to the level of the shoulder or a leg to the level of the hip.
- Regularly apply a clean, dry dressing to the area. But do not tape it to the skin. Gently hold it in place with a soft bandage. Only put on a lymphoedema bandage if your lymphoedema specialist has shown you how to do it.

Having lymphorrhoea can be upsetting. You may find it difficult to manage, but specialist support can help you. If lymphorrhoea is affecting how you feel about your body, we have more information about body image in our **Body image and cancer** booklet (page 100).

**“ My Macmillan nurse was there for me in what could have been a very lonely time. Reassurance from a family member is not the same as reassurance from a professional who understands the whole experience physically. ”**

Anne, living with lymphoedema



# Coping with lymphoedema

Living with lymphoedema	76
Your sex life	79
Travel and lymphoedema	81

# Living with lymphoedema

Because lymphoedema is a long-term (chronic) condition, it is important to stay involved in your lymphoedema care.

It can be hard to take all the precautions and do all the treatments that your lymphoedema specialist advises. It can take up a lot of your time, and you may need extra support from friends and family. Contacting others through a support group or our Online Community (page 103) can also help keep you motivated.

There are things you can do to stay healthy and as involved in your own healthcare as possible.

**“ I had an operation to remove the lymph nodes when I was 21, and Macmillan now help me manage my treatment and offer information and advice. ”**

Karen, living with lymphoedema

## Your follow-up

It is important to have regular check-ups with your lymphoedema specialist or doctor. Here are some things that might happen at your appointments:

- The specialist will check the skin and tissues in the swollen area.
- The specialist may take photographs of the area to monitor progress.
- Depending on the swelling, the specialist might think about changing the size of your compression garment.
- Your specialist may measure your arm or leg if those areas are affected. It could be helpful for you to keep a progress chart where you can write down the measurements each time.

Try to follow the advice your lymphoedema specialist gives you about managing and treating the lymphoedema. When your specialist has reduced your lymphoedema as much as possible, they may discharge you. After this, you will manage it yourself at home. It is always possible to get referred back to the specialist if things change.

If you have any worries, tell your lymphoedema specialist or doctor. You should be able to contact them between appointments if you have any problems.

## Keeping to a healthy weight

If you have lymphoedema, or are at risk of developing it, it is important to try and stay a healthy weight. Being overweight puts more stress on the lymphatic system. This makes lymphoedema harder to manage and treat. It is also more difficult to put compression garments on and they may not fit as well.

It can be difficult to lose weight and keep to a healthy weight. Sometimes, people find they have gained weight because of treatment. For example, you may gain weight if you have had treatment for breast cancer.

If possible, try to keep your weight within the normal range for your height. Your GP or practice nurse can tell you what your ideal weight is. You may find it helpful to ask your GP for advice and support. They may refer you to a dietitian.

### **Tips for keeping to a healthy weight**

- Reduce your calorie intake by cutting down on fat and sugar in your diet.
- Only eat as much food as you need.
- Eat a balanced diet with lots of fruit and vegetables – this will give you all the nutrients you need to keep your body healthy.
- Increase your physical activity to help you burn calories – always get advice from your lymphoedema specialist or doctor before you start.
- It is best to avoid losing weight too quickly with an extreme diet. Losing weight slowly is healthier and you are more likely to keep the weight off.

### **Keeping a food diary**

Some people with lymphoedema feel that certain foods can increase swelling. These include:

- spicy food
- salty food
- alcohol (especially wine).

There is no medical evidence to say that food or drinks can increase lymphoedema swelling. But if you feel that some foods make it worse, you can write them down as a reminder to avoid them.

# Your sex life

Lymphoedema can affect your sex life. It can also change the way you see and feel about your body. This is called your body image.

Coping with lymphoedema might make you feel too tired to have sex. Sometimes, it can make it physically difficult to have sex. For example, it can be difficult to have sex if you have swelling in your genitals. You can get advice about this from your doctor or lymphoedema specialist.

You may need time to adjust. As the lymphoedema improves and you get used to managing it, you may feel more like having sex.

To make sex more comfortable and enjoyable, you may want to:

- find sexual positions that do not put weight on the area affected by lymphoedema
- have sex when there is less swelling – for many people this is in the morning, or after wearing a compression garment for a few hours
- use extra lubricant if you have genital lymphoedema, to reduce friction to the skin
- have sex while partly dressed, or in dimmed light, if you feel very self-conscious.

## You and your partner

You may worry that your partner no longer finds you attractive. If you do not have a partner, you may worry about having a physical relationship in the future.

It may help to talk to your partner about your concerns. Talking can help you understand each other better. Sharing your feelings can help your confidence. Partners are often concerned about how to express their love physically and emotionally. Cuddles, kisses and massages are affectionate and sensual ways of showing how much you care for someone. You could do these even if you do not feel like having sex.

## Getting help

Many people feel embarrassed or self-conscious talking about sex. It is important to remember that your lymphoedema specialist or doctor is used to talking about this. They can suggest where you could get extra help and support. If you need more expert help, they can refer you to a psychologist, counsellor or sexual therapist.

We have more information in our booklets **Cancer and your sex life** and **Body image and cancer** (page 100).

# Travel and lymphoedema

If you are planning to go away on holiday, you may worry about managing your lymphoedema. Planning ahead for your trip should help you manage any possible problems and enjoy your time away.

It is important to maintain your usual routine for managing your lymphoedema. But there are other things you need to be careful of when travelling.

You may find these checklists useful to help you plan ahead.

## Before you go

Here are some tips for planning for a trip:

- If you need any vaccinations before your holiday, do not have them in an affected limb.
- If you are planning a more active holiday, talk to your lymphoedema specialist before you go. They can give you advice about avoiding stress to the affected area.
- If you have had cellulitis in the past, ask your GP about antibiotics to take with you. If you develop cellulitis while away, you can start taking them at the first sign of infection. It can be helpful for your lymphoedema specialist to speak with your GP about this.
- Pack an antiseptic cream in case you get a cut, scratch or bite in the affected area.
- Pack an insect repellent. You need one that contains at least 50% DEET. This is the active ingredient in insect repellent. A pharmacist can help you choose the best one for you.

- If you are taking any prescription drugs with you, make sure you have enough to last the duration of your trip. You may also need a letter from your doctor.
- Make sure you have travel insurance. You can find more information about cancer and buying travel insurance on our website **[macmillan.org.uk/buying-travel-insurance](https://www.macmillan.org.uk/buying-travel-insurance)** and in our booklet **Travel and cancer** (page 100).

## During your journey

Here are some tips for when you are travelling:

- You may be planning to go on a plane and use a compression garment. You will need to wear it for a few hours before the flight, during the flight and for a few hours afterwards. Any increased swelling during the flight should reduce afterwards.
- When you travel on a plane or train, try to move around a lot and do gentle stretching exercises. You can ask your lymphoedema specialist what exercises might help. You could book an aisle seat, so you have more room to move.
- During longer car journeys, stop regularly to get out and walk around.
- Wear comfortable, loose-fitting clothes and shoes.
- When on a plane, wear flight socks that fit well. Your GP or specialist nurse can give you advice if you cannot find a pair that fit.
- Use a suitcase with wheels – this can be easier than carrying a heavy bag.
- Avoid lifting and pulling heavy luggage with your affected arm. Ask someone to help.

## While you are away

Here are some tips for when you are on holiday:

- If you have lymphoedema in your leg, do not walk barefoot on the beach or around a swimming pool. This reduces the risk of cuts and possible infection in your foot.
- Sunburn can increase swelling. If you are in a hot climate, it is important to wear good quality suncream. Look for a sun protection factor (SPF) of 50. Sit in the shade or cover the affected area with a hat, long-sleeved shirt or loose trousers.
- Drink plenty of water. This will help to keep your skin in good condition.
- Sea salt and chlorine make the skin dry. If you go swimming, shower afterwards and put on moisturiser.
- If you are using a sauna or having hot baths, only spend a short amount of time in them to begin with. This will allow you to check how it affects swelling.
- Keep the affected area as cool as possible.
- If you start to get signs of an infection, you should arrange to visit a doctor straight away. Your hotel, accommodation host or travel representative can help you find someone locally. Signs of an infection could be flu-like symptoms including high temperature, redness or heat in the affected area. It may also include increased swelling. If you have antibiotics with you, start taking them as soon as possible.

We have more information about travel and cancer on our website **[macmillan.org.uk/travel-and-cancer](https://www.macmillan.org.uk/travel-and-cancer)**

You can also contact the Lymphoedema Support Network (page 106). It has a more detailed guide on holidays and travel for people with lymphoedema.



# Work and financial support

Work	86
Help with money and benefits	88

# Work

## Employment rights

The Equality Act 2010 protects anyone who has, or has had, cancer. Even if you had cancer in the past that was successfully treated and now cured, the act still covers you. This means your employer must not discriminate against you for any reason, including any past cancer diagnosis. The Disability Discrimination Act protects people in Northern Ireland.

For most people, returning to work is a big step in their recovery. Many companies have an occupational health service. Occupational health departments can offer confidential support and counselling before and after your return to work.

Late effects, such as lymphoedema, may make work more difficult. Your employer has a duty to make reasonable adjustments to your workplace or working arrangements.

These may include:

- different working hours, such as working part-time, having a flexible start or finish time or working from home
- giving you time off to go to medical appointments or for rehabilitation
- allowing extra breaks so that you can move around
- changing your job description to remove tasks that are particularly difficult for you.

Sometimes, these adjustments may be expensive. A government-funded scheme called Access to Work may help your employer with financial and practical support. You can find out more at [gov.uk/access-to-work](https://gov.uk/access-to-work)

We have more information in our booklet **Work and cancer** (page 100).

There is also lots more information online at [macmillan.org.uk/work](https://macmillan.org.uk/work)



# Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to. We also have information for carers (page 100).

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- **gov.uk** if you live in England or Wales
- **socialsecurity.gov.scot** if you live in Scotland
- **nidirect.gov.uk** if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced money advisers. You can speak to them by calling the Macmillan Support Line on **0808 808 00 00**. Please note the opening times may vary by service.

You can also get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland (pages 111 to 112).

Our booklet **Help with the cost of cancer** has more information. You can order our booklets for free. Visit **orders.macmillan.org.uk** or call us on **0808 808 00 00**.



## Grants

You may be able to get some financial help from other charities, for example one-off grants. For further information, contact the Macmillan Support Line.

## Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance.

If you are thinking about buying insurance or making a claim, one of our money advisers can help. You can call them on **0808 808 00 00**.

We have more information in our booklet **Travel and cancer**. Our Online Community forum on Travel insurance may also be helpful. Visit **[macmillan.org.uk/community](https://macmillan.org.uk/community)**



# Your feelings

Your feelings

92

# Your feelings

You may feel a range of emotions about lymphoedema. While it is not a life-threatening condition, it can change your body and affect your lifestyle in different ways. It can also be a reminder of your cancer experience. Any negative feelings often get easier to cope with as the lymphoedema improves and you get used to managing it.

## Feeling self-conscious

You may feel self-conscious or embarrassed about the effects of lymphoedema on your body.

Although it can take time, it is usually possible to reduce lymphoedema. As this happens, you may become less self-conscious about it. Some people find wearing different types of clothing, such as looser styles, helps them cope with changes in their body.

It may be helpful to prepare a way of explaining lymphoedema to people who ask questions or make comments. It is your decision how much you want to say about your condition, or whether you say anything at all. Other people who have lymphoedema, or your lymphoedema specialist, may be able to help you with this. Some people find our Online Community (page 103) a helpful way to find support from others in a similar situation.

We have more information about coping with changes to your body image in our booklet **Body image and cancer** (page 100).

## Feeling responsible

Some people worry that there is something they could have done to prevent lymphoedema. The lymphoedema is a result of cancer treatment or of the cancer itself. We still do not know enough about why lymphoedema develops in certain people. It is important to remember it is not your fault. Lymphoedema can still develop in people who do everything they can to reduce their risk.

## Feeling angry

It is natural to feel angry about having lymphoedema when you have already had to cope with cancer. It may have developed when you thought life was starting to get back to normal. You may feel angry about the extra time and effort you need to make to take care of yourself and manage lymphoedema. It can help to talk to others about how you feel.

Finding ways to help you relax and reduce stress can help with any anger you might feel. This can include:

- talking about, or writing down, how you feel
- gentle exercise
- breathing or relaxation therapy
- yoga or meditation.

As the lymphoedema reduces and you learn to manage it, you may feel more able to do things you enjoy. Or you may find new activities to replace the things that are now harder to do.

## Feeling low

Lymphoedema is an ongoing problem, and at times you may feel sad or depressed about your situation. Try to let family and friends know how you are feeling. This can help them support you.

Some people feel sad because they do not have enough support. For some people, family and friends may live far away. It is normal to have times when you want to be left alone to cope with your feelings. But if you avoid people often, and feel anxious and sad for a long time, talk to your doctor or nurse.

Some of the emotional signs of depression can include:

- feeling low in mood most, or all, of the time
- having no interest in or getting no enjoyment from things you usually enjoy
- feeling helpless or hopeless
- feeling numb, overwhelmed or out of control
- always worrying.

You may find it helpful to read our booklet **How are you feeling? The emotional effects of cancer** (page 100).



## Talking to others or sharing your experience

Talking about your feelings may help reduce feelings of stress, anxiety and isolation. There are lots of different ways to communicate, and these can all help you feel less alone. Some people find joining a support group or our Online Community helpful (page 103). The nurses at your hospital can give you information about support groups in your area.

If you need more support, you can contact the Macmillan Support Line (page 102). You can talk to one of our cancer support specialists.

### If you need more help

Talking about your feelings is not always easy. It is important to be kind to yourself. You should not feel guilty about needing extra help to deal with your emotions. These feelings can be very difficult to cope with. This happens to lots of people.

If you feel anxious, panicky or sad a lot of the time talk to your doctor or nurse. You should also talk to them if think you may be depressed. They can often refer you to a counsellor or psychologist for specialist help. Sometimes, a course of anti-depressant drugs can be helpful.

We have more information about the emotional effects of cancer on our website at **[macmillan.org.uk/emotions](https://www.macmillan.org.uk/emotions)** This includes the feelings you may have and suggestions for coping with them.

## Support groups

Self-help or support groups offer a chance to talk to other people who may be in a similar situation. They may be facing the same challenges as you. Joining a group can be helpful if you live alone. Or they may be helpful if you do not feel able to talk about your feelings with people around you. Not everyone finds talking in a group easy. You can go and find out what a support group is like before you decide to get involved.

We have information about cancer support groups across the UK (page 103). Your lymphoedema specialist may also know about groups in your area.

## Online support

Many people get support through the internet. There are online support groups, social networking sites, forums, chat rooms and blogs for people affected by cancer. You can use these to:

- meet and talk to other people affected by cancer
- chat in real time
- share your experiences and feelings
- ask questions
- give advice based on your experience to other people.

Our Online Community (page 103) is a social networking site. It lets you talk to people online, blog about your journey, make friendships and join support groups. You can share your own experiences and feelings, and get support from others.



# Further information

About our information	100
Other ways we can help you	102
Other useful organisations	106
Your notes and questions	115

# About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

## Order what you need

You may want to order more booklets or leaflets like this one.

Visit **orders.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

## Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

## Other formats

We also provide information in different languages and formats, including:

- audiobooks
- eBooks
- Braille
- large print
- British Sign Language
- translations.
- easy read booklets

Find out more at **macmillan.org.uk/otherformats**

If you would like us to produce information in a different format for you, email us at **informationproductionteam@macmillan.org.uk** or call us on **0808 808 00 00**.

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call **0808 808 00 00** and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

## Macmillan Information and Support Centres

Our Information and Support Centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

Find your nearest centre at [macmillan.org.uk/informationcentres](https://macmillan.org.uk/informationcentres) or call us on **0808 808 00 00**.

## Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

### Financial advice

Our expert money advisers on the Macmillan Support Line can help you deal with money worries and recommend other useful organisations that can help.

### Help accessing benefits

You can speak to our money advisers for more information. Call us free on **0808 808 00 00**. Visit [macmillan.org.uk/financialsupport](https://macmillan.org.uk/financialsupport) for more information about benefits.

# Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

## Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

## Macmillan Support Line

Our support line is made up of specialist teams who can help you with:

- emotional and practical support if you or someone you know has been diagnosed with cancer
- clinical information from our specialist nurses about things like diagnosis and treatments
- welfare rights advice, for information about benefits and general money worries.

To contact any of our teams, call the Macmillan Support Line for free on **0808 808 00 00**. Or visit **macmillan.org.uk/support**-line to chat online and find the options and opening times.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to **macmillan.org.uk/talktous**

## Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help bring people together in their communities and online.

### Support groups

Whether you are someone living with cancer or a carer, family member or friend, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

### Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

You can also use our Ask an Expert service on the Online Community. You can ask a money adviser, cancer information nurse or an information and support advisor any questions you have.



## **Macmillan healthcare professionals**

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

## **Help with work and cancer**

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work.

Visit **[macmillan.org.uk/work](https://macmillan.org.uk/work)**

# Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

## **Lymphoedema support organisations**

### **British Lymphology Society**

**[www.thebls.com](http://www.thebls.com)**

Produces guidelines for health professionals. Has a directory of lymphoedema treatment services.

### **Lymphoedema Support Network (LSN)**

Helpline **020 7351 4480**

**[www.lymphoedema.org](http://www.lymphoedema.org)**

Provides information and support to people affected by lymphoedema. Runs a helpline and produces a range of leaflets and DVDs.

### **Lymphoedema Network Northern Ireland**

Tel **0771 014 5368**

**[www.lnni.org](http://www.lnni.org)**

Produces information about lymphoedema, including exercises for arms and legs. Has information about lymphoedema services in Northern Ireland.

## **Lymphoedema Support NI**

Helpline **028 9066 7570**

**[www.lymphoedemasupportni.org](http://www.lymphoedemasupportni.org)**

Provides information and support for people with lymphoedema in Northern Ireland. Has a telephone helpline and a support group.

## **Manual Lymphatic Drainage UK**

Tel **0844 800 1988**

**[www.mlduk.org.uk](http://www.mlduk.org.uk)**

Has a national and international register of MLD UK accredited therapists.

## **Compression garment and specialised footwear suppliers**

Your GP can prescribe garments, but usually only on the recommendation of your lymphoedema specialist. Your specialist will discuss which is the most appropriate garment for you and choose the correct size. Your GP will then be asked to provide the garment. If you have questions about your garment, you can speak to your lymphoedema specialist or contact the supplier.

## **BSN Medical Ltd**

Tel **0148 267 0100**

**[www.bsnmedical.co.uk](http://www.bsnmedical.co.uk)**

## **Cosyfeet**

Tel **0145 829 3128**

**[www.cosyfeet.com](http://www.cosyfeet.com)**

### **Credenhill Limited**

Tel **0800 195 0650**  
**www.credenhill.co.uk**

### **Haddenham Healthcare Ltd**

Tel **0184 420 8842**  
**www.hadhealth.com**

### **Juzo UK Ltd**

Tel **0161 358 0104**  
**www.juzo.com/en-uk**

### **Medi UK Ltd**

Tel **0143 237 3500**  
**www.mediuk.co.uk**

### **Sigvaris Britain Ltd**

Tel **0126 432 6666**  
**www.sigvaris.co.uk**

## **General cancer support organisations**

### **Cancer Black Care**

Tel **020 8961 4151**  
**www.cancerblackcare.org.uk**

Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

## **Cancer Research UK**

Helpline **0808 800 4040**

**[www.cancerresearchuk.org](http://www.cancerresearchuk.org)**

A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

## **Macmillan Cancer Voices**

**[www.macmillan.org.uk/cancervoices](http://www.macmillan.org.uk/cancervoices)**

A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

## **Maggie's**

Tel **0300 123 1801**

**[www.maggies.org](http://www.maggies.org)**

Has a network of centres in various locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

## **Penny Brohn UK**

Helpline **0303 3000 118**

**[www.pennybrohn.org.uk](http://www.pennybrohn.org.uk)**

Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

## **General health information**

### **Health and Social Care in Northern Ireland**

#### **[www.northerntrust.hscni.net](http://www.northerntrust.hscni.net)**

Provides information about health and social care services in Northern Ireland.

### **NHS.UK**

#### **[www.nhs.uk](http://www.nhs.uk)**

The UK's biggest health information website. Has service information for England.

### **NHS 111 Wales**

#### **[111.wales.nhs.uk](http://111.wales.nhs.uk)**

NHS health information site for Wales.

### **NHS Inform**

Helpline **0800 22 44 88**

#### **[www.nhsinform.scot](http://www.nhsinform.scot)**

NHS health information site for Scotland.

### **Patient UK**

#### **[www.patient.info](http://www.patient.info)**

Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health and illness related websites.

## **Counselling**

### **British Association for Counselling and Psychotherapy (BACP)**

Tel **0145 883 300**

**[www.bacp.co.uk](http://www.bacp.co.uk)**

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'How to find a therapist' page.

### **UK Council for Psychotherapy (UKCP)**

Tel 020 **7014 9955**

**[www.psychotherapy.org.uk](http://www.psychotherapy.org.uk)**

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

## **Financial support or legal advice and information**

### **Advice NI**

Helpline **0800 915 4604**

**[adviceni.net](http://adviceni.net)**

Provides advice on a variety of issues including financial, legal, housing and employment issues.

### **Benefit Enquiry Line Northern Ireland**

Helpline **0800 232 1271**

Textphone **028 9031 1092**

**[www.nidirect.gov.uk/money-tax-and-benefits](http://www.nidirect.gov.uk/money-tax-and-benefits)**

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

### Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use its online webchat or find details for your local office by contacting:

#### England

Helpline **0800 144 8848**  
**[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)**

#### Scotland

Helpline **0800 028 1456**  
**[www.cas.org.uk](http://www.cas.org.uk)**

#### Wales

Helpline **0800 702 2020**  
**[www.citizensadvice.org.uk/wales](http://www.citizensadvice.org.uk/wales)**

### Emotional and mental health support

#### Mind

Helpline **0300 123 3393**  
**[www.mind.org.uk](http://www.mind.org.uk)**

Provides information, advice and support to anyone with a mental health problem through its helpline and website.

## **Samaritans**

Helpline **116 123**

Email **jo@samaritans.org**

**www.samaritans.org**

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

## **Equipment and advice on living with a disability**

### **British Red Cross**

Tel **0344 871 11 11**

**www.redcross.org.uk**

Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

### **Disability Rights UK**

Tel **0330 995 0400** (not an advice line)

**www.disabilityrightsuk.org**

Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

### **Living Made Easy**

Helpline **0300 999 0004**

**www.livingmadeeasy.org.uk**

Provides free, impartial advice about all types of disability equipment and mobility products.

## **Motability Scheme**

Tel **0300 456 4566**

**[www.motability.co.uk](http://www.motability.co.uk)**

The scheme enables disabled people to exchange mobility allowances they have as part of benefits (including the enhanced rate mobility component of Personal Independence Payment) to lease a new car, scooter or powered wheelchair.

## **Scope**

Helpline **0808 800 3333**

Textphone Call **18001** from a textphone followed by **0808 800 3333**.

**[www.scope.org.uk](http://www.scope.org.uk)**

Offers advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.

## **LGBT-specific support**

### **LGBT Foundation**

Tel **0345 330 3030**

**[www.lgbt.foundation](http://www.lgbt.foundation)**

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information about sexual health, relationships, mental health, community groups and events.

### **OUTpatients**

**[www.outpatients.org.uk/](http://www.outpatients.org.uk/)**

A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage.

Also produces resources about LGBT cancer experiences.

OUTpatients runs a peer support group with Maggie's Barts.

[illegible]

## This image shows a single sheet of white paper with horizontal green ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

## Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

## Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Senior Medical Editor, Prof Tim Iveson, Consultant Clinical Oncologist.

With thanks to: Yolande Borthwick, Lymphoedema Specialist Nurse; Josie Cameron, Breast Advanced Practitioner; Ioanna Nixon, Consultant Clinical Oncologist; Rhian Noble-Jones, Lymphoedema Specialist Physiotherapist; Sally Shanley, Breast Care Nurse Specialist; and Melanie Thomas, National Clinical Lead for Lymphoedema in Wales.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact **[informationproductionteam@macmillan.org.uk](mailto:informationproductionteam@macmillan.org.uk)**

### Sources

Below is a sample of the sources used in our lymphoedema information. If you would like more information about the sources we use, please contact us at **[informationproductionteam@macmillan.org.uk](mailto:informationproductionteam@macmillan.org.uk)**

British Lymphology Society. Skin care for people with lymphoedema. 2022.

Lymphoedema Support Network and British Lymphology Society. Guidelines on the management of cellulitis in lymphoedema. 2022.

O'Donnell TF et al. Systematic review of guidelines for lymphedema and the need for contemporary intersocietal guidelines for the management of lymphedema. Journal of Vascular Surgery: Venous and Lymphatic Disorders. 2020.

## Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

### 5 ways you can help someone with cancer

#### 1. Share your cancer experience

Support people living with cancer by telling your story, online, in the media or face to face.

#### 2. Campaign for change

We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

#### 3. Help someone in your community

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

#### 4. Raise money

Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

#### 5. Give money

Big or small, every penny helps. To make a one-off donation see over.

## Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £  
(Please delete as appropriate)

I enclose a cheque / postal order /  
Charity Voucher made payable to  
Macmillan Cancer Support  
OR debit my:

Visa / MasterCard / CAF Charity  
Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date     /     /

## Do not let the taxman keep your money

Do you pay tax? If so, your gift  
will be worth 25% more to us –  
at no extra cost to you. All you  
have to do is tick the box below,  
and the tax office will give 25p  
for every pound you give.

☐ I am a UK tax payer and  
I would like Macmillan Cancer  
Support to treat all donations  
I make or have made to  
Macmillan Cancer Support in the  
last 4 years as Gift Aid donations,  
until I notify you otherwise.

I understand that if I pay less Income Tax  
and/or Capital Gains Tax than the amount of  
Gift Aid claimed on all my donations in that  
tax year it is my responsibility to pay any  
difference. I understand Macmillan Cancer  
Support will reclaim 25p of tax on every £1 that  
I give.

Macmillan Cancer Support and our trading  
companies would like to hold your details in  
order to contact you about our fundraising,  
campaigning and services for people affected  
by cancer. If you would prefer us not to use  
your details in this way please tick this box. ☐

In order to carry out our work we may need  
to pass your details to agents or partners who  
act on our behalf.

If you would rather donate online  
go to **macmillan.org.uk/donate**



Registered with  
**FUNDRAISING  
REGULATOR**



Please cut out this form and return it in an envelope (no stamp required) to: Supporter donations,  
Freepost RUCY-XGCA-XTHU, Macmillan Cancer Support, PO Box 791, York House, York YO1 0NJ

**This booklet is about lymphoedema. It is for anyone who has lymphoedema, or is at risk of developing it. This booklet may also be helpful for family members, friends or carers.**

---

The booklet explains the signs and symptoms of lymphoedema and how you may be able to reduce your risk of developing it. It explains how it is diagnosed, and how it may be treated. It also has information about feelings, practical issues and money.

At Macmillan we know cancer can disrupt your whole life. We'll do whatever it takes to help everyone living with cancer in the UK get the support they need right now, and transform cancer care for the future.

For information, support or just someone to talk to, call **0808 808 00 00** or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

Need information in different languages or formats? We produce information in audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

---



Trusted  
Information  
Creator

Patient Information Forum