MACMILLAN
CANCER SUPPORT

UNDERSTANDING LYMPHOEDEMA

> ‘On days when I’m mostly sedentary, I get up and walk around at work, take a brisk 10 minute walk, or try to do something active like gardening when I get home.’

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 it developing. It explains how it is diagnosed and how it may be treated. It also has information about emotional, practical and financial issues.

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.

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 NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

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

How to use this booklet

The 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.

We have included quotes from people who have lymphoedema. Some quotes are from **healthtalk.org** Some names have been changed. 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**

Contents

LYMPHOEDEMA


Worcestershire Acute Hospitals NHS Trust NHS
Nicky Plant
Gynae - Oncology
Nurse Specialist

What is lymphoedema?

Lymphoedema is swelling that develops because of a build-up of lymph fluid in the body's tissues. The lymphatic system (see page 8) usually drains the fluid away. Lymphoedema happens when the lymphatic system is not working properly. It can happen anywhere in the body, including the arms, legs, head and neck, chest area and genital area.

Lymphoedema is a chronic swelling. That means it never goes away completely, because you cannot undo the causes (see pages 16 to 17). But it is usually possible to reduce the swelling, especially if it is diagnosed early. Specialists in lymphoedema can assess and treat it. They can also teach you how to manage it yourself.

There are some videos about lymphoedema on our website that you may find helpful **macmillan.org.uk/lymphoedemavideos**

The lymphatic system

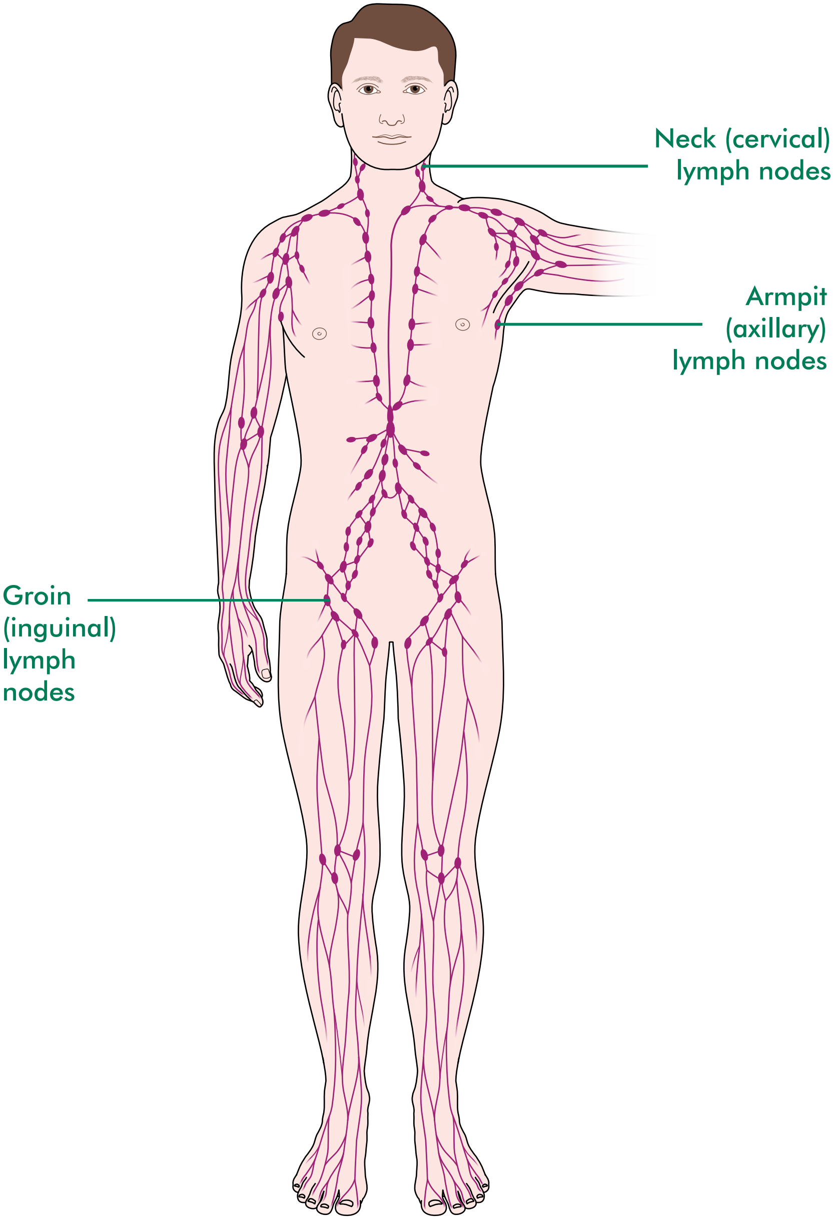
To understand lymphoedema, it helps to know about the lymphatic system.

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.

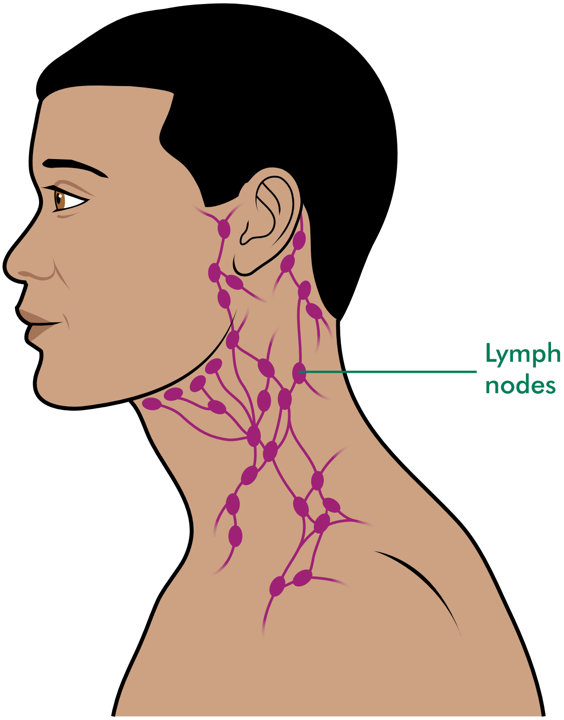
The lymphatic system does different things:

- 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.

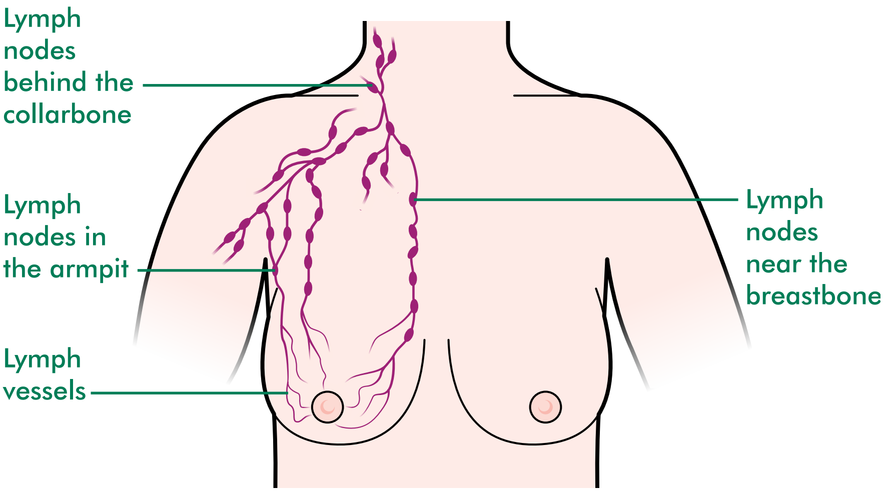
The lymphatic system



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 (see page 9), 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.

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.

We have more information about these different types of cancer (see page 114).

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.

How lymphoedema develops

Sometimes, lymph nodes or vessels are damaged, blocked or removed. This makes it is harder for lymph fluid to drain. The fluid can then build up between the tissues and 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. Or doctors 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. It is usually possible to reduce the swelling if it is diagnosed and treated early. But it does not go completely. This is known as 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 (see pages 26 to 31).

Causes of lymphoedema

Not everyone who has lymphoedema has had cancer. But cancer or its treatment can cause lymphoedema. This may be because of:

- **surgery to remove lymph nodes** – interrupting the normal flow of the lymphatic system (see pages 8 to 9) and causing fluid to build up in the affected area
- **radiotherapy to the lymph nodes** – causing hardening of the tissue (scar tissue) that blocks the flow of lymph fluid
- **cancer cells spreading to the lymph nodes** – causing a blockage that leads to a build-up of fluid
- **a cancer that is pressing on the lymph vessels** – causing a blockage in the lymph nodes close by that leads to a build-up of fluid.

Lymphoedema after cancer treatment

Lymphoedema can develop weeks, months or even years after cancer treatment. The most common places for lymphoedema to develop after cancer treatment are in the arm or leg.

You may get lymphoedema in **the arm** after breast cancer or melanoma treatment (surgery or radiotherapy) to the armpit.

It may also develop in **the leg** if cancer or its treatment affects the lymph nodes in the pelvis or groin area. This usually happens after surgery or radiotherapy for gynaecological cancers (cancer of the womb, cervix, ovary, or vulva) or anal cancer. Or it can happen after treatment to the lymph nodes in the groin for melanoma.

Other areas lymphoedema can develop in are:

- **the breast or chest area**, after breast cancer treatment
- **the pelvic area and genitals**, after surgery or radiotherapy to lymph nodes in the pelvis for cancers of the prostate, bladder, womb, vagina, testicles, penis or rectum
- **the face, head** and neck, after surgery or radiotherapy to lymph nodes in the neck.

We have more information about the cancer types listed above (see page 114). If you have surgery, it is common to get swelling (oedema) near the surgery scar in the first days after the operation. This can take several weeks to go completely. This type of swelling is not the same as lymphoedema. If lymphoedema develops after surgery to remove the lymph nodes, it usually happens a few months or years later. If you are worried about any swelling, always talk to your doctor or nurse.

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

> ‘The doctors explained about lymphoedema before surgery and before radiotherapy. They gave me leaflets explaining what it was and how to manage it.’
>
> **Anne**

Signs and symptoms

The signs and symptoms of early lymphoedema include:

- **swelling** – you may notice your clothing, shoes or jewellery (rings or watches) feeling tighter than usual, even before you see any swelling
- **changes in sensation** – the limb or area may feel heavy, tight, full or stiff
- **skin changes** – the affected area may feel tight, stretched or a thicker texture, and sometimes it can be dry, flaky, rough or scaly
- **aching in the affected area**.

If you have any of these symptoms, ask your doctor or specialist nurse for advice as soon as you notice them. This can help to reduce the risk of the lymphoedema getting worse.

> ‘My groin started to swell and it was really sore, so I phoned the helpline. They said it’s because the lymphatic fluid has nowhere to go, so it’s just collected in the body.’
>
> **Mark**

Other symptoms

The symptoms vary depending on how much lymphoedema there is, 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 (pitting oedema). In later stages, the skin tissue often hardens or becomes more fatty.

There may also be more complex skin problems (see pages 78 to 83). Sometimes, lymph fluid leaks from the skin (called lymphorrhoea). This is due to fluid building up in the tissues, or 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.

Diagnosis

If you have any signs or symptoms of lymphoedema, contact your hospital doctor, specialist nurse, physiotherapist or GP. Treatment can improve lymphoedema. The earlier you start treatment, the more successful it is likely to be.

Your doctor, specialist nurse or physiotherapist will ask you about the signs or symptoms you have. They will also look at the swollen limb or area. Knowing which cancer and treatments you have had helps them assess whether lymphoedema is causing your symptoms.

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 a cancer that is affecting the lymph nodes is causing the lymphoedema.

Lymphoedema specialist

If your doctor, specialist nurse or physiotherapist thinks you have lymphoedema, they should refer you to a lymphoedema specialist. The lymphoedema specialist will then confirm the diagnosis. Health professionals with specialist knowledge in treating lymphoedema may include:

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

In this information, the term lymphoedema specialist refers to any one of these health professionals.

Organisations such as the Lymphoedema Support Network and the British Lymphology Society can advise about specialist services near you (see page 119). The Lymphoedema Support Network also has advice for GPs who are having difficulty referring to a lymphoedema service.

> ‘My arm swelled and it was lymphoedema. It’s taken 14 years to affect me. But with exercise and wearing a sleeve, it’s under control.’
>
> **Rashid**

Assessment

The lymphoedema specialist will assess how much the lymphoedema is affecting you.

Your specialist will:

- ask you 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 lymphoedema specialist should always carry out a full assessment. This is so they can decide the best way to treat the lymphoedema.

REDUCING YOUR RISK OF LYMPHOEDEMA

Ways to reduce your risk of lymphoedema

This information is for people who do not have lymphoedema, but are at risk of getting it. It gives you information about how to reduce your risk.

Anyone who has had cancer treatment that affects their lymph nodes is at risk of developing lymphoedema.
The risk is greater if:

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

We have more information about radiotherapy in our booklet **Understanding radiotherapy**. We also have more information about radiotherapy and surgery on our website (see page 114).

> ‘I will always have to be careful with my legs as I am at risk of getting lymphoedema, but I am aware of how to manage it.’
>
> **Annabel**

You may have had just one or two lymph nodes removed (called a sentinel lymph node biopsy or SLNB). The sentinel node is the first node (or nodes) that lymph fluid drains to from a part of the body. Or your doctors may have removed a complete group of nodes (called lymph node clearance). If you have had an SLNB, you are still at risk of getting lymphoedema, but the risk is lower.

We do not know why some people develop lymphoedema after cancer treatments and others do not. Straining the limb or having a skin infection 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. 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 or infected. It is also important to protect your skin from cuts and grazes, insect bites and sunburn.

We have more detailed information about skin care for lymphoedema (see pages 38 to 43).

Watch for early signs of infection

It is important to be aware of early signs of infection in the area at risk of lymphoedema. Doctors can then treat the infection straight away with antibiotics. Contact your GP straight away if you have flu-like symptoms or a high temperature or fever. You should also contact them if you notice any of the following in the area that is at risk:

- redness or warmth
- a new painful swelling
- pain or tenderness
- red streaks that go up or down.

Try to exercise and keep active

Muscle activity helps improve the flow of lymph fluid in the body. 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, to 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. There may be some exercises you need to be more careful doing. 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.

Physical activity will help you feel better generally, and keep your weight down. It encourages deeper breathing, which helps lymph fluid flow. Breathing exercises on their own, or as part of yoga or pilates, can also help (see page 68).

Ask your physiotherapist or specialist nurse for advice about exercise. We have more information about exercising and keeping active to reduce lymphoedema (see pages 44 to 48). You can find more general information about keeping active in our booklet **Physical activity and cancer treatment** (see page 114).

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 (see pages 87 to 88). We also have general information about healthy eating and weight management. You may find our booklets **Healthy eating and cancer** and **Managing weight gain after cancer treatment** useful (see page 114).

Take care when travelling

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

- Avoid sitting in one position for the whole journey.
- Move around often, and do gentle stretching exercises if you are on a plane or train.
- During longer 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, so you do not need to carry a heavy bag.

If you do not have lymphoedema, you do not usually need to wear a compression garment (see page 53) when on a plane. But tell your doctor if you are flying a long distance and have had swelling caused by cancer or its treatment. They will be able to advise you on what to do. They can tell you how helpful a compression garment might be in your situation.

We have more information about travelling when you have lymphoedema (see pages 92 to 96).

TREATING LYMPHOEDEMA

Treatment for lymphoedema

Treatment for lymphoedema aims to reduce and control swelling, help with discomfort, and 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 right treatment for your situation. You will usually have more than one type of treatment, as they work better when used together.

The main treatments for lymphoedema are:

- skin care (see pages 38 to 43)
- exercise and keeping active (see pages 44 to 48)
- positioning of the limb or area (see pages 49 to 51)
- compression (see pages 52 to 61)
- a type of massage called lymphatic drainage (see pages 62 to 67).

You may have other treatments (see pages 76 to 77), 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 (see pages 70 to 73). This includes the breast or chest, head and neck area and the genitals.

To start with, you may have more regular treatment from your lymphoedema specialist. After this, the specialist will talk to you about how you can manage the lymphoedema yourself (see page 37).

Avoiding pressure on the area

Along with treatment, 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:

- having your blood pressure taken in the affected arm
- wearing tight jewellery such as rings, watches, bracelets, ankle bracelets or toe rings
- wearing tight clothing such as tops with tight armholes, waist bands or bra straps.

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

Self-managing lymphoedema

Learning how to manage lymphoedema yourself is the main part of treatment. This means you have less 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 (see pages 66 to 67).

> ‘I go to a lymphoedema clinic twice a year. But I’ve got a phone number to call in between my appointments if I need to.’
>
> **Betty**

Skin care

It is important to look after and protect your skin to avoid any injury or infection. If you have lymphoedema or are at risk of it (see pages 26 to 27), you are also at risk of a skin infection called cellulitis (see pages 78 to 79). Good skin care helps reduce this risk.

Tips for 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 your skin stay in good condition by 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 chemist. 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).

Here are some more things you can do:

- Keep your skin clean. Wash with warm water every day. If you have dry skin, use soap-free cleansers.
- After washing, carefully dry the area. If the lymphoedema is in a limb, make sure you dry in between fingers or toes of the affected limb.
- If lymphoedema affects your feet, use surgical spirit or alcohol wipes daily between your toes. This helps prevent athlete’s foot (a fungal infection). You can use anti-fungal powder to treat signs of athlete’s foot, for example having peeling, itchy skin.

Cuts, grazes, burns and bites

You are more likely to get an infection if your skin is broken. It is impossible to avoid all skin injuries. So 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 break does not heal, or shows any sign of infection (see pages 78 to 79).

Tips for avoiding cuts and grazes

It is impossible to avoid all skin injuries. But there are things that you can do to reduce the risk.

Household tasks

Doing some household tasks can increase your risk of injuring your skin. These include washing up, DIY, gardening or cooking. Depending on where the lymphoedema is, you could wear long sleeves, gloves, or long trousers to help reduce this risk.

Pets

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.

Removing hair

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. Always test a small area first.

Cutting your nails

Use nail clippers instead of scissors to cut your nails. You are less likely to cut the skin with 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 the nails on your feet. They can refer you to a foot specialist (chiropodist). Tell the chiropodist that you have lymphoedema, or that you are at risk of it.

Exercise

Exercise 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. Or they may suggest other sports you can try instead.

Shoes

If you have lymphoedema in a leg, think about what you wear on your feet. It is best to wear shoes that fit well, protect your feet and do not rub. It is safest not to walk around barefoot. This is in case you step on something, or stub your toe.

Tips for avoiding burns and bites

Insect repellent

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. This 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 a sun cream with a sun protection factor (SPF) 50. You should not use a sunbed.

Other tips for avoiding skin damage

Lymphoedema alert bracelet

When seeing health professionals, always tell them about your lymphoedema. This is because they may need to give you injections, vaccinations, a drip (infusion), or acupuncture. If you need to have any of these, they should try to avoid putting needles into the affected area. There is no strong medical evidence to say this will increase your risk of getting lymphoedema. But most experts see it as a precaution to reduce the risk of infection. 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) (see page 119).

Tattoos

Talk to your doctor or nurse before getting a tattoo on the area affected by, or at risk of lymphoedema.

Tips for avoiding temperature extremes

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

- Avoid using saunas, hot tubs and steam rooms.
- 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 scalding yourself.

Exercise and keeping active

Exercise is an important part of lymphoedema treatment. It can improve lymphoedema because it:

- increases the flow of lymph fluid by working your muscles
- helps lymph fluid move away from the swollen area
- strengthens your muscles
- keeps your joints flexible, maintaining and improving your range of movement
- improves your posture.

Exercise can also help you maintain a healthy weight. This can help to reduce lymphoedema swelling. It can also help you feel better in yourself, and reduce stress and anxiety.

The exercise you do will depend on your level of fitness. It could be gentle stretches, or something that you enjoy or have enjoyed before. The most important thing is to do it regularly. If you have not done exercise for a while, it is best to start slowly and build up.

Gentle stretching exercises can help reduce and control lymphoedema. Your lymphoedema specialist will explain the best exercises for you. They will also tell you how many times a day you should do them. We describe some simple exercises to reduce arm and leg swelling on page 48. Talk to your lymphoedema specialist about other exercises you are thinking of doing.

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

The right amount of exercise or activity will vary from person to person. 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) – see pages 78 to 79.

Keeping physically active

Keep using your affected limb for all your normal activities. Doing things around the house or in the garden is another form of exercise.

Start gently with most activities and slowly increase the intensity. Depending on the level of swelling you have, you may find some activities difficult until the swelling improves. Take care with anything that might cause muscle strain.

> ‘I had to find the right level of exercise intensity. I’ve taken up swimming which I’ve found very beneficial.’
>
> **Barny**

Other types of exercise and lymphoedema

It is usually fine to continue exercising if you did before, as long as you start slowly and build up. In the past, health professionals were worried that exercise might make lymphoedema worse. But studies, mostly looking at people with arm lymphoedema, are showing that this is not true. There may be some types of exercise that you will need to take more care with. For example, 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.

Swimming, walking, doing stretching exercises and yoga are all good types of exercise. Swimming is helpful if you have problems with your joints, as it does not put strain on them.

If you become more breathless or uncomfortable than expected during exercise, or if swelling gets worse, stop straight away. You should ask your specialist for advice.

We have more information about physical activity during and after cancer treatment in our booklet **Physical activity and cancer treatment** (see page 114).

Exercises to reduce arm swelling

Here are some simple exercises to reduce arm swelling:

- 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.
- With your arm supported, try bending and straightening it at the elbow.
- Check that your shoulders are level by looking at your posture in the mirror. Practise shrugging, and then dropping your shoulders slowly to the count of five.
- Slowly circle your shoulders in one direction, then the other.

Lymphoedema Network Northern Ireland produce two leaflets that you may find useful (see page 119). They explain how to do exercises for arms and legs.

Exercises to reduce leg swelling

Do the following exercises regularly while you are resting:

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

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

Positioning and moving the area affected by lymphoedema

Careful positioning when resting or sitting can reduce swelling for lymphoedema in an arm, leg, or the head and neck. Avoid sitting with your legs down. This causes the fluid to drain into your feet and calves. Also, moving your muscles helps move fluid around the body. So regular, gentle movement or exercise stops fluid building up.

These tips will help you correctly position the area affected by lymphoedema.

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 it 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.

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, exercises can help stop fluid building up:

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

> ‘On a normal day I’m lucky and do not to have any significant problems. Although if I’m sitting down, I’ll put my feet up whenever possible.’
>
> **Anne**

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

Compression can help reduce and control lymphoedema. It works by:

- limiting lymph fluid build-up
- helping move fluid to an area that is draining well
- providing support that helps muscles pump fluid away
- putting more pressure on certain areas, to help drain more fluid.

You can have compression in different ways. The best way for you depends on how much swelling you have, and what area is affected. Your lymphoedema specialist will discuss this with you.


Fitting a compression garment

Compression garments

Your lymphoedema specialist may prescribe and fit you with a compression garment. This is to help control the lymphoedema. You may have sleeves for swollen arms and stockings for swollen legs. You can also get compression garments for lymphoedema that affects the breast, chest and genital areas.

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 shades to match different skin tones. There are 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.

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

You may have lymphoedema in your fingers or toes. If so, you may need a garment for these areas, as well as 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 remove it. Here are some tips:

- 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, one bit at a time. Make sure you do not pull it up by the top of the garment.
- Do not turn or roll the top over – this will restrict the blood flow and cause more swelling.
- Using a little unperfumed talc on your arm or leg can help ease the garment on. There are also different things available to help put garments on and to take them off. Your lymphoedema specialist will be able to give you information about suppliers.
- 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. If you have an arm sleeve, you should put the glove on the opposite hand.
- Moisturise your skin at night after you take off your garment. Do not do this in the morning, because cream makes the sleeve or stocking difficult to put on.

For arm sleeves

For arm sleeves, start by folding the top down to the elbow or until the garment is in half. You could also hold onto something like a doorknob or handle to help. You can pull against it to pull the sleeve up your arm.

For leg sleeves

For leg garments, it may help to turn the stocking inside out as far as the ankle or heel part.

> ‘It’s just like putting your shoes on every day. I get up and I put my sleeve on, it’s just a part of me and I’m glad it’s under control.’
>
> **Irene**

Wearing compression garments

It is important to wear your compression garment all day. You can usually take it off at night, when you are lying down and resting.

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.

You will get at least two garments, so you can have one 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.

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

> ‘I wear a ‘sleeve’ to contain the swelling – but it doesn’t interfere with my day-to-day activities.’
>
> **Naomi**

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

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

- numbness
- pins and needles
- pain
- a change of colour of your fingers or toes.

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.

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 from a spray bottle, 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.

When travelling a long distance, 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.

When not to use compression garments

There are some situations when you should not wear compression garments. You should avoid wearing one if:

- the skin is fragile or damaged
- the skin is pitted, folded or leaking lymph fluid
- you have cellulitis 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 your limb is large and irregular in shape, you may get compression bandaging (see next page). This is to try and make the limb smaller before you are fitted with a compression garment.

Compression bandages

Rarely, your arm or leg can get very swollen or change a lot in shape. This means it may be difficult to fit a compression sleeve or stocking.

To reduce the swelling and improve the shape, you may have special multi-layer lymphoedema bandages. You will also have padding with the bandages.

Sometimes, you have bandaging if the skin is fragile. This is because putting on and removing a compression garment could cause damage.

A lymphoedema specialist will usually put the compression bandages on for you every 1 or 2 days. It may take 2 or 3 weeks of bandaging before it is possible to fit a compression sleeve or stocking.

There are other types of compression systems that are like wraps. They have straps that overlap. Velcro keeps them in place. Wraps can be easier for you to manage yourself. They can also be more effective when swelling is harder to control.

Compression pumps

Sometimes, your lymphoedema specialist may use compression pumps to treat lymphoedema in a limb. If they recommend this, they will show you how to use one at home. It may be possible to borrow a pump from your local hospital, as they are expensive to buy. Your lymphoedema specialist can give you more information.

The pump uses electricity. It has a power unit, and an inflatable sleeve that you put on your arm or leg. When you turn the pump on, the sleeve slowly inflates for a few minutes. It then deflates for a few minutes. Your lymphoedema specialist will tell you which pressure to use. Do not use higher pressures than this, as it could make the swelling worse.

Before using the pump, it is important to do simple lymphatic drainage (SLD) (see page 66) or manual lymphatic drainage (MLD) (see page 63). You need to have this to your body (trunk) and at the top of the affected limb. This is to drain lymph fluid from these areas, before the pump moves more fluid out of your affected limb.

Tips for using a pump

- Do not use the pump if you have an infection or inflammation in the affected limb.
- Always remove your compression garment before using the pump. Put it back on as soon as you have finished.
- When using the pump, support your arm on the arm of your chair. Or rest your leg up on a sofa or bed. This will help with drainage.
- If you feel any pain, stop straight away and tell your doctor.
- Watch for more swelling or thickening at the top of the limb, where the pump sleeve stops. If this happens, ask your lymphoedema specialist for advice.

What is 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 two 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.

> ‘I see my wonderful lymphoedema nurse Judy every few months. She gave me massage instructions and advice on support garments. I try to do the massage most days.’
>
> **Anne**

Manual lymphatic drainage (MLD)

You should only have MLD by a trained therapist. There are several different techniques. They are all similar, but use different massage movements.

The different methods are:

- Casley-Smith
- FG-MLD
- Földi
- Leduc
- Vodder.

Your therapist can tell you more about the method they use and what it involves.

You usually have MLD along with compression garments or bandaging (see pages 53 and 59) to keep the swelling down. But it can be particularly useful in areas where it is difficult to use compression therapy. Breathing techniques (see page 68) are also an important part of this treatment.

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 (see page 120). They keep a register of their members. Or the British Lymphology Society (see page 119) has a directory on its website that you may find helpful.


The Bowen Technique

Having MLD

When you start, you will usually have MLD daily, then it will reduce to 2 or 3 times a week. 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. 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) (see page 66).

You will not have MLD if you have an infection (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 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. Usually, you do not massage the swollen area. They can also show a friend or relative to do it.

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 own 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 (see page 68).

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 that is away from the swelling. You could use a little talcum powder if your skin is sticky and your hand does not move freely. If your skin is red when you have finished, then the movement is too much.

The Lymphoedema Support Network (see page 119) 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. You should talk to your lymphoedema specialist before buying one. Some people find it helpful to use a soft-bristled baby’s brush as a massager.

Deep breathing exercises

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

You might find it helpful to listen to our CD **Relax and breathe**, which can help with deep breathing. You can also contact our cancer support specialists for more information (see page 116).

Treating lymphoedema in more difficult to treat areas

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 (see pages 38 to 43). Exercising, keeping to a healthy weight and taking good care of yourself (see pages 87 to 88) are also important. Your specialist will explain the best way of managing and treating lymphoedema in other parts of your body.

We have more information about exercise and weight management (see page 114).

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 the shoulder straps on a bra dig in. If you need to wear a prosthesis, try to get a lightweight one. Your lymphoedema specialist 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, to make sure they fit properly. It can also be helpful to wear a sports bra.

You may also need to wear a compression sleeve. This is to stop the fluid moving from one area to another. It can also help improve drainage. You do not often have compression bandaging (see page 59) 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) (see page 66) to treat breast and chest lymphoedema.

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

Lymphoedema taping (Kinesio® taping)

This is a special taping technique that goes directly onto the skin (see page 76). 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 may help lymph fluid close to the skin flow more easily.

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 (see pages 63 and 66).

You may have specially made compression garments (see page 53). 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 (see page 59) 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 (see page 77). 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 (see pages 62 to 67). Sometimes, you can have Kinesio® taping (see page 76). You may have special, low-pressure compression garments to use in this area of the body (see page 53). But you should never have compression to the neck area. You sometimes have surgery to treat lymphoedema of the eyelids (see page 77).

OTHER WAYS OF TREATING LYMPHOEDEMA

Other treatments

Sometimes, you may have other treatments alongside skin care, keeping active, positioning of the limb or area, compression and lymphatic drainage (see Treating lymphoedema section on pages 33 to 73).

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 also tell you where to buy the tape from.

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. The 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 (see page 59). You should also keep the limb raised for a few days. About 2 weeks after the operation, you have the bandages removed. You then get a compression garment (see page 53) 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 it from getting worse. Research is happening to find out more about its possible benefits. So at the moment, it is not widely available.

Managing problems caused by lymphoedema

Recognising infection

It is important to know the signs of an infection. 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 an infection in the skin (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)
- lose your appetite.

If you have any of these signs, contact your GP straight away. They will usually prescribe a course of antibiotics, which you should start straightaway. If it happens over the weekend, do not wait to see your GP. Contact your out of hours GP service – these are different depending on whether you live in England, Scotland, Wales or Northern Ireland. You can get details of these services from your GP. You should also contact your lymphoedema specialist. They will usually tell you to stop all lymphoedema treatment.

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 still wear it, even if you are still taking antibiotics.

Guidance on using antibiotics

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 called the consensus document on the management of cellulitis in lymphoedema. It is available from the British Lymphology Society (see page 119).

The guidance says that someone with lymphoedema who develops cellulitis, should start taking antibiotics as soon as possible. They should take the antibiotics for at least 2 weeks (14 days) as prescribed, until all signs of infection have gone.

If you have had an infection, it may be useful to keep antibiotics with you at home. You can also take antibiotics with you when you travel abroad. You can discuss this with your GP or lymphoedema specialist.

The consensus document suggests the following antibiotics:

- amoxicillin or flucloxacillin
- clarithromycin or erythromycin, if you cannot take penicillin
- clindamycin, if the infection does not start to get better after 48 hours.

It is also important to rest, and keep the affected area raised. You should remove compression garments (see page 53) if they are painful. You not should 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 into a vein (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.

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.

What 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 (see page 59) if your lymphoedema specialist has shown you how to do it.

Having lymphorrhoea can be upsetting, but specialist support can help you. We also have more information about body image in our booklet **Body image and cancer** that may help (see page 114).

COPING WITH LYMPHOEDEMA

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 can also help keep you motivated (see page 117).

The information on pages 86 to 101 explains some things you can do to stay healthy and as involved in your own healthcare as possible.

Your follow-up

It is important to have regular check-ups with your lymphoedema specialist or doctor. During these appointments, they will check the skin and tissues in the swollen area. The specialist may take photographs of the area to monitor progress. Or they may look at changes in size of your compression garment. If your arm or leg is affected, your specialist may measure it. It may 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 has given 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, talk them over with 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, this can happen after 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 or a dietitian for advice and support.

Our booklet **Healthy eating and cancer** has more information (see page 114).

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 lets you get all the nutrients you need to keep your body healthy.
- Increase your physical activity (see pages 44 to 48) 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 find certain foods, such as spicy and salty foods or alcohol (especially wine), can increase swelling. Write down any foods you think make your lymphoedema worse 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 (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, 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 the swelling is less – 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 what you could do for 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 about sexuality and cancer. We also have more information on cancer and body image (see page 114).

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 carry on with 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.

> ‘I always wear compression garments when I fly and pack some bandages when I go away for a few days. I also have a small antiseptic spray in my wash bag, in case I graze my leg.’
>
> **Steve**

Before you go

- 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 advise you how to plan your trip so you do not put too much stress on the affected area.
- If you have had cellulitis (see page 78 to 79) in the past, ask your GP about antibiotics to take with you (see pages 80 to 81). 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. Your pharmacist can advise you which might be best.
- If you are taking any prescription drugs with you, make sure you have enough to last. You may also need a letter from your doctor. We have more information about some prescription drugs on our website (see page 114).
- Make sure you have travel insurance (see page 101).

Helen, living with lymphoedema

During your journey

Here are some tips for when you are travelling:

- You may be planning to go on a plane and have a compression garment (see page 53). You will need to wear it for a few hours before, during and for a few hours after the flight. Any increased swelling during the flight should reduce afterwards.
- When you travel on a plane or train, move around a lot and do gentle stretching exercises. You can ask your lymphoedema specialist what exercises might help (see page 48). 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

- If you have lymphoedema in your leg, do not walk barefoot on the beach or around the 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 sun cream. 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.
- Avoid saunas and hot baths. Keep the affected area as cool as possible.
- If you start to get signs of an infection, let a doctor know straight away. These signs 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 in our booklet **Travel and cancer** (see page 114).

You can also contact the Lymphoedema Support Network (see page 119). It has a more detailed guide on holidays and travel for people with lymphoedema.

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 (changes) to your workplace and working practices.
These may include:

- allowing some flexibility in working hours
- allowing extra breaks so that you can move around
- removing tasks from your job that you may find physically challenging
- letting you work from home.

Sometimes, these adjustments may be expensive. For these, a government-funded scheme called Access to Work may help your employer with financial and practical support.

We have more information about work and cancer (see page 114).

Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Wales and Scotland or **nidirect.gov.uk** if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by cancer.

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who cannot work because of illness or disability. There are different types of ESA:

- Contribution-based ESA may be available if you have paid enough National Insurance.
- Income-related ESA may be available if your income and savings are low, or if you cannot get contribution-based ESA. Income-related ESA is gradually being replaced by a new benefit called Universal Credit.

Personal Independence Payment

This benefit is for people aged between 16 and 64 who have problems moving around and looking after themselves. You must have had these difficulties for at least 3 months and expect them to last for at least 9 months.

Attendance Allowance

This benefit is for people aged 65 or over who have problems looking after themselves because of an illness or disability. This could mean getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months.

Special rules

If you are terminally ill, and your doctor thinks you may be expected to live for less than 6 months, you can apply for some benefits using a fast-track process called special rules. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

Gary, living with lymphoedema

Help for carers

Carer's Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you do not qualify for it, you can apply for Carer's Credit.

Carer's Credit helps prevent gaps in your National **Insurance** record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are looking into buying insurance or making a claim, one of our financial advisers can help. Call **0808 808 00 00**.

We have more information in our booklets **Insurance** and **Travel and cancer**. Our Online Community forum **Travel insurance** may also be helpful (see page 117).

YOUR FEELINGS

Your feelings

You may feel a range of emotions about lymphoedema. Although it is not a life-threatening condition, it changes your body and affects 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 (see page 117) 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** (see page 114).

Clare, living with lymphoedema

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 to take care of yourself and manage lymphoedema (see pages 86 to 87). 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 low 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 low 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.

There is more information in our booklet **How are you feeling?** (see page 114).

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 (see page 117) helpful. 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 (see page 116). 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, and sometimes people need more help. This happens to lots of people and does not mean you are not coping.

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 (see page 114). 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 along to see what a support group is like before you decide to get involved.

We have information about cancer support groups across the UK (see page 117). Your lymphoedema specialist may also know about groups in your area.

> ‘It can help to stay positive and get out and about when you can – the best thing for me is company.’
>
> **Pat**

Online support

Many people now 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 keep in touch with 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 (see page 117) is a social networking site. It lets you talk to people in our chat rooms, blog about your journey, make friendships and join support groups. You can share your own experiences and feelings, and get support from others.


TALKING ABOUT CANCER
CLOSE TO YOU HAS CANCER
TALKING TO CHILDREN AND TEENAGERS WHEN AN ADULT HAS CANCER
THE BUILDING-UP DIET
HEALTHY EATING AND CANCER

FURTHER INFORMATION

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 leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

Online information

All of our information is also available at **macmillan.org.uk/information-and-support** There you'll also find videos featuring real-life 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
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats** If you'd like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email **reviewing@macmillan.org.uk** You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're 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 free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.
Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.
Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

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's why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, 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**

The Macmillan healthcare team

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.

> 'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'
>
> **Mal**

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you're 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**

My Organiser app

Our free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

Other useful organisations

There are lots of other organisations that can give you information or support.

Lymphoedema support organisations

British Lymphology Society
www.thebls.com
Produces guidelines for health professionals. Has a directory of lymphoedema treatment services on the website.

Lymphoedema Support Network (LSN)
Helpline 020 7351 4480
(Mon to Fri, 9.30am to 4.30pm)
Email admin@lsn.org.uk
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 028 9504 8545
Email info@lnni.org
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
Email info@lymphoedemasupportni.org
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
Email admin@mlduk.org.uk
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 when recommended by 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, you can speak to your lymphoedema specialist or contact the supplier.

BSN Medical Ltd

Tel 01482 670100
Email
orders.uk@bsnmedical.com
www.bsnmedical.co.uk

Credenhill Limited

Tel 0115 932 0144
Email sales@credenhill.co.uk
www.credenhill.co.uk

Haddenham Healthcare Ltd

Tel 01844 208842
Email sales@hadhealth.com
www.hadhealth.com

Juzo UK Ltd

Tel 0161 358 0104
Email sales@juzo.co.uk
www.juzo.com

Medi UK Ltd

Tel 01432 373500 (Mon to Fri, 8.30am to 5pm)
Email enquiries@mediuk.co.uk
www.mediuk.co.uk

Sigvaris Britain Ltd

Tel 01264 326 666
www.sigvaris.co.uk

Cosyfeet

Tel 01458 447275 (Mon to Fri, 8.30am to 5.30pm, and Sat, 9am to 1pm).
Email comfort@cosyfeet.com
www.cosyfeet.com

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 Focus Northern Ireland

Helpline 0800 783 3339
(Mon to Fri, 9am to 1pm)
Email
nurseline@cancerfocusni.org
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

Cancer Research UK

Helpline 0808 800 4040
(Mon to Fri, 9am to 5pm)
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Cancer Support Scotland

Tel 0800 652 4531
Email info@cancersupportscotland.org
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Maggie's Centres

Tel 0300 123 1801
Email
enquiries@maggiescentres.org
www.maggiescentres.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
(Mon to Fri, 9.30am to 5pm)
Email
helpline@pennybrohn.org.uk
www.pennybrohn.org.uk

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

Riprap

www.riprap.org.uk

Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.

Tenovus

Helpline 0808 808 1010
(Daily, 8am to 8pm)
Email
info@tenovuscancercare.org.uk
www.tenovuscancercare.org.uk

Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)

Tel 01455 883 300
Email bacp@bacp.co.uk
www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

Samaritans

Helpline 116 123
Email jo@samaritans.org
www.samaritans.org

Samaritans branches are located across England, Ireland, Scotland and Wales. Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

UK Council for Psychotherapy (UKCP)

Tel 020 7014 9955
www.psychotherapy.org.uk

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

Financial or legal advice and information

Benefit Enquiry Line Northern Ireland

Helpline 0800 220 674
(Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)
Textphone 028 9031 1092
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 their online webchat or find details for your local office in the phone book or one of these websites:

England

Helpline 03444 111 444
www.citizensadvice.org.uk

Scotland

Helpline 0808 800 9060
www.citizensadvice.org.uk/scotland

Wales

Helpline 03444 77 2020
www.citizensadvice.org.uk/wales

Northern Ireland

Helpline 0800 028 1181
www.citizensadvice.co.uk/nireland

Civil Legal Advice

Helpline 0345 345 4345
(Mon to Fri, 9am to 8pm, and Sat, 9am to 12.30pm)
Minicom 0345 609 6677
www.gov.uk/civil-legal-advice
Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English isn't your first language.

Department for Work and Pensions (DWP)

Personal Independence Payment (PIP)
Helpline 0345 850 3322
Textphone 0345 601 6677
(Mon to Fri, 8am to 6pm)
Carer's Allowance Unit
Tel 0800 731 0297
Textphone 0800 731 0317
(Mon to Fri, 8am to 6pm)
www.gov.uk/carers-allowance
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

GOV.UK

www.gov.uk
Has information about social security benefits and public services in England, Scotland and Wales.

Money Advice Scotland

Helpline 0141 572 0237
Email info@moneyadvicescotland.org.uk
www.moneyadvicescotland.org.uk
Use the website to find qualified financial advisers in Scotland.

National Debtline (England, Wales and Scotland)

Tel 0808 808 4000
(Mon to Fri, 9am to 8pm, and Sat, 9.30am to 1pm)
www.nationaldebtline.org
A national helpline for people with debt problems. The service is free, confidential and independent. Has an online chat service with an expert debt advisor.

NiDirect

www.nidirect.gov.uk
Has information about benefits and public services in Northern Ireland.

Personal Finance Society – 'Find an Adviser' service

www.thepfs.org/yourmoney/find-an-adviser
Use the website to find qualified financial advisers in your area of the UK.

The Money Advice Service

Helpline
0800 138 7777 (English)
0800 138 0555 (Welsh)
(Mon to Fri, 8am to 6pm)
Typetalk 18001 0300 500 5000
Email enquiries@moneyadviceservice.org.uk
www.moneyadviceservice.org.uk
Runs a free financial health check service and gives advice about all types of financial matters across the UK.
Has an online chat service for instant money advice.

Equipment and advice on living with a disability

British Red Cross

Tel 0344 871 11 11
Textphone 020 7562 2050
Email
contactus@redcross.org.uk
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
Email enquiries@disabilityrightsuk.org
www.disabilityrightsuk.org
Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support.

LGBT-specific support

LGBT Foundation

Tel 0345 330 3030
(Mon to Fri, 10am to 10pm, and Sat 10am to 6pm)
Email helpline@lgbt.foundation
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Disclaimer

Thanks

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

With thanks to: Julie Cunneen, Lymphoedema Clinical Nurse Specialist; Sue Desborough, Lymphoedema Specialist Occupational Therapist; Dr Ioanna Nixon, Consultant Clinical Oncologist; Ali O'Connor, Independent Lymphoedema Specialist Nurse; and Emma Underwood, Lymphoedema Specialist Occupational Therapist.

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 **cancerinformationteam@macmillan.org.uk**

Sources

We have listed a sample of the sources used in the booklet below. If you would like further information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

British Lymphology Society, Consensus Document on the Management of Cellulitis in Lymphoedema. 2016.
British Lymphology Society, Standards of Practice for Lymphoedema Services. 2016.
International Society of Lymphology, The Diagnosis and Treatment of Peripheral. 2016.

Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're 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're there 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

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

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.

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?

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

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

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 / /

Don't 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.

Registered with
FUNDRAISING
REGULATOR

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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 it developing. It explains how it is diagnosed, and how it may be treated. It also has information about emotional, practical and financial issues.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) 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 NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

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