
LYMPHOEDEMA - A PATIENT GUIDE

What is Lymphoedema?

Lymphoedema is a chronic swelling of parts of the body, caused by a build up of fluid (lymph) in the tissues. It can happen as a result of damage or disruption to your lymphatic system from a tumour or during or after cancer treatment such as surgery or radiotherapy. It can develop in any area of the body, however it is more common in the arms or legs. It can occur at any time during or after your cancer treatment.

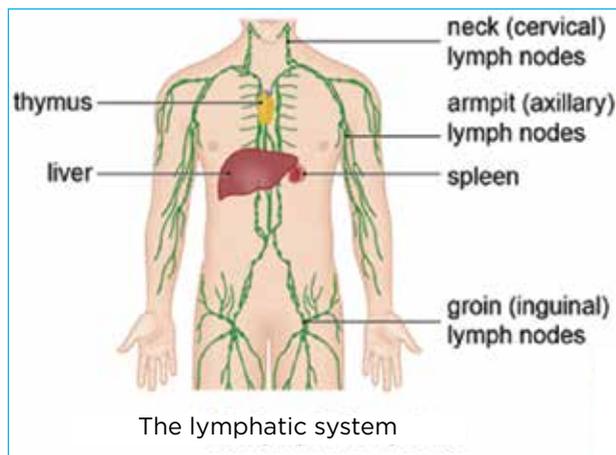
This booklet focuses mainly on lymphoedema which is caused by cancer or cancer treatment. However, there are other causes of lymphoedema as well as other forms of swelling (oedema) that are not related to the lymphatic system (therefore not called lymphoedema).

If you have any questions about other causes of lymphoedema or oedema ask your doctor or therapist.



The lymphatic system

The lymphatic system is a one way drainage system in your body which is made up of lymph nodes and lymphatic vessels. It helps to drain excess fluid from your tissues back into the bloodstream and helps to transport



proteins, fat cells, hormones and waste products. The lymph nodes also help your body to fight infection and other diseases such as cancer by filtering out harmful or damaged cells, bacteria, viruses, and waste products. Once broken down by the lymph nodes these cells are transported via the lymphatic system to the bloodstream to be eliminated by the body with its other waste products.

How does swelling occur?

Fluid and nutrients leave the bloodstream to bathe and support the tissue. About 90% of this fluid returns directly to the bloodstream, but the rest is absorbed by the lymphatic system and transported back to the bloodstream which it re-enters near the neck.

Swelling can occur when there is damage or blockage to the lymphatic system from surgery, radiotherapy, infection, or the tumour itself. As a result the lymphatic system is not able to drain fluid properly so it builds up in the tissues, causing lymphoedema, or swelling.

What happens if I develop lymphoedema?

If you develop lymphoedema you will be referred to see one of our therapists who can help you manage your lymphoedema. Lymphoedema is a chronic condition which cannot be cured; however with treatment and good self management we aim to control your swelling and reduce your symptoms.

What are the symptoms of lymphoedema?

- swelling
- pain and discomfort
- tightness and stretching of your skin
- heavy or full feeling
- problems moving your joints
- dry or thick skin

What treatments are available?

Lymphoedema treatment aims to:

- teach you about lymphoedema and how to manage the condition confidently

- reduce swelling and prevent progression
- improve symptoms
- prevent or manage skin changes or infections

There are a number of different treatments available for managing lymphoedema. The techniques used by your therapist and the frequency of treatment will vary depending on your symptoms and the severity of your condition.

If you have severe or complicated swelling you may need to undergo an initial intensive course of treatment followed by a maintenance period. If your swelling is not severe you may start off on a maintenance form of treatment. Your therapist will talk to you about the best course of treatment for you during your initial assessment.

Lymphoedema management generally focuses on four key components:

- skin care
- Manual Lymphatic Drainage (MLD/ SLD)
- compression (compression garments, or multilayer bandaging)
- exercise

Skin care

Skin care is one of the most important aspects in managing your lymphoedema. By taking care of your skin you can help to prevent skin changes that can occur with lymphoedema, such as dryness or cracking, and prevent infections. Infections are more likely to occur because the lymph fluid in the tissues is rich in protein which means it is an ideal environment for bacteria to breed. There are also a reduced number of lymph nodes to fight off infections.

You can look after your skin by:

- Checking your skin daily for any signs of cracks, cuts, dry areas, infections, or rashes. Pay particular attention to areas such as between the fingers and toes or skin folds.
- Ensuring that you wash the affected area daily with warm water. You should use a soap substitute as soaps and shower gels will do little to hydrate the skin. There are a number of products available from your chemist or supermarket and it is important to find a product that is suitable for you. Some commonly used products include Aqueous cream or E45. Adverse effects to soap substitutes are uncommon however can occur and may include stinging, discomfort, irritation, or an allergic reaction. If you experience any adverse reactions to a product cease using that product and if required seek medical advice. Be aware that bathing areas can become slippery if you are using one of these products.
- Ensuring that you dry the area thoroughly, especially between your

fingers, toes, or skin folds to help prevent fungal infections. If you develop a fungal infection you can use an antifungal cream or powder which are available from your chemist. Always read the patient information leaflet that comes with your medicine. You will need to disinfect any footwear or clothing that have come into contact with the infected area. If you have an infection on your feet you may need to see a chiropodist.

- Moisturising daily with an un-perfumed moisturising cream or ointment. You can get these from your chemist or on prescription from your GP. Some commonly used moisturiser creams include Aveeno or E45. It is important to find a product that is suitable for you.
- Being aware of signs of infection such as redness, heat, tenderness, blistering, fever, or feeling generally unwell. If you notice any of these symptoms you should consult your doctor as you may need a course of antibiotics. Cellulitis is an infection of the skin and subcutaneous tissues (tissues beneath the skin) from bacteria entering through any cracks or cuts in the skin. If you suspect that you have cellulitis you should consult your doctor immediately.

Other skin care tips include the following:

- Be careful when cutting or filing your fingernails/toenails and removing unwanted body hair. Use an electric razor if shaving.
- Try to avoid having injections or blood pressure taken on the affected limb.
- Protect the limb from sunburn by wearing appropriate sun protection or covering up.
- If your legs are affected ensure that you are wearing well fitted shoes to prevent blisters forming.
- If your arms are affected wear gloves for daily activities such as gardening or washing up.
- Take care when cooking to avoid any burns to your hands and arms.
- Avoid wearing tight sleeves or jewellery on the affected area.
- If you receive any scratches or bites to the affected area ensure that they are kept clean. It is helpful to carry a small tube of antiseptic cream with you to be used as required.
- Avoid excess heat such as saunas and very hot baths or showers as this can increase swelling.

Medical / Manual Lymphatic Drainage (MLD)

MLD is a manual technique performed by your therapist to encourage the re-absorption of fluid and proteins from the swollen tissue back into the circulation. It assists in clearing lymphatic channels and redirecting lymphatic flow.

MLD is a specialised technique and can only be performed by a trained

therapist. If you are receiving MLD as part of your treatment you may need to undress as the technique requires skin contact.



Self/Simple Lymphatic Drainage (SLD)

SLD is a modified form of MLD that you can do yourself at home. Depending on the type of lymphoedema you have, this technique may or may not be appropriate for you. Your therapist will teach you appropriate SLD techniques if they feel it would benefit your treatment.

Compression garments

As part of your treatment you may be fitted with a compression garment. The compression garment will help to prevent further swelling in the tissues, and improve the movement of fluid from your tissues into the lymphatic system. It will also help to prevent re-accumulation of fluid in the tissues after your treatment. The pressure garment provides a firm resistance for the muscles to work against allowing fluid to be drained more effectively.

Compression garments are used in long term management of your lymphoedema. You may need to wear the garments long term to maintain a reduction in your swelling. With this in mind it is important that they are comfortable and easy to apply. Ensure that you inform your therapist if you have any concerns regarding your garment.

Many garments are now available on NHS GP prescription.

Putting the garment on:

- Try not to pull it up by the top band as it will overstretch the material.
- Turn the garment two thirds inside out and pull the first third on, then slowly inch the rest of the garment on. This will ensure the pressure is even and you will get the correct compression.
- All folds and wrinkles should be smoothed out.

- Products are available to assist you in putting the garment on if you are finding it too difficult. Please ask your therapist for more information.

Wearing your garment

- Your garment should feel firm, but not cause pain or discomfort. It should not rub. Initially it may take some time to get used to wearing your garment. If you are finding it very difficult to wear please inform your therapist.
- It should usually be worn all day and removed at night however your therapist/nurse will advise you as to your individual requirements.
- Put it on first thing in the morning when the arm or leg is less swollen. Do not moisturise the limb immediately before donning the garment as it may damage the garment. It is better to moisturise at night time.
- If you experience rubbing in the elbow/knee or other creases, try some Vaseline to help the material glide over the area.
- Do not wear it with the top or bottom folded over as this can restrict circulation.
- Do not cut or alter the shape of the garment as it will reduce its effectiveness.

Remove the garment if you experience any of the following:

- It causes or increases pain.
- It causes numbness or pins and needles.
- You notice a significant change of colour (dusky, purple, white) in your finger or toe tips.
- The skin breaks down.
- The fingers/toes become very cold.
- The swelling increases quickly.

Caring for your garment

- Have two garments so you can wear one whilst the other one is being washed. The elastic fibres require humidity therefore you need to wash the garments regularly.
- The garments should be replaced every 3-6 months or when they begin to lose their elasticity. Very active clients may require replacement more often.
- Wash them according to the manufacturer's instructions - usually at about 40° in a mild washing powder or liquid (as for woollens or delicate fabrics). Do not use a detergent.
- Dry on flat towel away from direct heat.

Compression bandaging

If your limb is very swollen, misshapen or if you have fragile skin a compression sleeve may be difficult to fit. Your therapist may recommend compression bandaging. This treatment technique aims to reduce the size of the swelling, improve the shape of the limb, improve the skin condition, and provide the muscles with a firm resistance to work against to assist with drainage of fluid.



There are two types of compression bandaging that are used depending on the individual:

1. Short stretch
2. Coban

Your therapist will discuss the differences in the two types of bandages with you and recommend the best option for you.

What compression bandaging involves:

- Frequent treatment sessions, usually for a period of 2-3 weeks. Each treatment session will be approximately one hour. Be aware you may need to attend for daily treatments. Your therapist will discuss this with you.
- Application of padding and multiple bandages to the limb which you will be required to wear for 24 hours or until your next treatment session.
- Treatment sessions will usually also include other lymphoedema treatment techniques such as MLD, exercise and skin care.
- You will be required to bring loose fitting clothes to fit over the bandages. If you are having your leg bandaged you will need to consider your foot wear.
- You will need to consider transport home as it may not be safe for you to drive.
- If you are working it is a good idea to discuss with your employers as it may limit your ability to perform your job.

Multilayer bandaging initially will feel very firm. This firmness will loosen after a few hours. If you are finding it too uncomfortable or you are noticing a change in colour of your finger or toe tips try moving them to assist with circulation. If this does not help you can undo the top bandage. If you are still very uncomfortable and unable to tolerate the bandage then please remove it.

Definitely remove your bandages if:

- It causes or increases pain.
- It causes numbness.

- You notice a significant change of colour in your finger or toe tips.
- The skin breaks down.
- The fingers/toes become very cold.
- The swelling increases quickly.
- You become short of breath. If this happens remove all your bandages and contact your therapist.

Your therapist will re-assess the bandaging at your next appointment.

Lymphoedema exercises

Exercise is an important part of your lymphoedema management. It will stimulate and encourage lymph flow and venous return to reduce swelling. Your lymphoedema therapist will provide you with appropriate exercises to do at home. When exercising you should wear your compression garments as this will facilitate lymph drainage. Lymphoedema exercises should be performed slowly, rhythmically and through range of movement. They are not aimed at increasing range of motion or muscle strengthening although this would be an added benefit.

Sport and fitness

It is advisable that you speak with your doctor or your therapist if you wish to start participating in an exercise programme. At Bupa Cromwell Hospital we offer a cancer recovery service to assist you in tailoring a well balanced physical activity programme, for both during and after your treatment. Please ask your therapist for more information about this service.

Regular physical activity can have a number of positive benefits for:

- Reducing the risk of cancer and increasing survivorship.
- Reducing the side effects of treatment.
- Improving psychological well being.
- Reducing fatigue.
- Maintaining physical and cardiovascular fitness.
- Reducing the risk of chronic diseases such as diabetes and heart disease.
- Reducing or preventing obesity. Obesity can increase your risks of developing a number of chronic diseases and tends to exacerbate lymphoedema. There is a direct link between maintaining a healthy weight and lymphoedema volumes.

Tips for exercise

- Wear your compression garment during exercise as it provides an external force for the muscles to pump against which will facilitate drainage of fluid. Sleeve compliance is a successful and simple management technique that forms a cornerstone of lymphoedema management.

- Ensure that you maintain a good posture throughout exercise. It promotes good quality movement and prevents possible soft tissue injury. Injury can result in increased inflammation and swelling to the area.
- If you want to participate in an exercise or sport that you have not done previously or have not performed for a long time it may be best to consult with your therapist first for advice. You should ease into any sport/ exercise starting with short training sessions and gradually increase duration and intensity as your fitness and strength improve. If you notice any increase in swelling you should cease that activity and inform your therapist.
- Try to avoid static exercises, i.e. holding a limb in one position. This can result in an increase in swelling. If you are performing an exercise where you are required to do a static task, such as gripping a racquet, ensure that you relax the hand and move it from time to time.
- Avoid lifting heavy weights and take care if you are doing an exercise that requires you to support your own body weight (for example push ups). Any activities which encourage fluid to the end of the limb should be undertaken with caution. Ask your therapist for further information and advice if you wish to start any of these types of exercises.
- Wear clothing that is appropriate to the exercise that you are participating in.
- Yoga is a good form of exercise that can encourage good breathing techniques, relaxation and stretching.
- Swimming is a good form of exercise as the body is supported by the water and the water itself gives some degree of compression. If you are currently having radiotherapy or intravenous chemotherapy treatment it is advisable to wait until your treatment has been completed and the skin has healed.

Other treatments offered at Bupa Cromwell Hospital

At Bupa Cromwell Hospital we strive to keep informed of current developments regarding lymphoedema and its management. We are continuously updating our clinical knowledge and practical expertise. Bupa Cromwell Hospital invests in specialised equipment to facilitate the management of lymphoedema, for example our low level laser therapy.

During your treatment your therapist may decide to include the use of other treatment modalities. These may include:

- Kinesiotaping: the application of a special latex free adhesive tape designed to create properties similar to that of the skin. When you move the body area where the tape is applied the tape stretches and lifts the skin creating space and facilitating drainage of fluid. It also helps to break down fibrosis and mobilise scar tissue in this way. It can be helpful to use on breast, hand, genital, and chest wall swelling.

- Laser therapy: low level laser therapy (LLLT) has beneficial effects on cells and tissues through assisting tissue repair, regeneration of lymphatic vessels and stimulating the activity of the immune system. Research has indicated reduction of pain, tightness, sensory symptoms and limb size following a regime of LLLT. An increase in ability to move the arm was also reported.
- Dynamic Intermittent Pneumatic Compression: this consists of a pump and an inflatable arm or leg piece. This inflatable sleeve is often made up of a number of segments which inflate and deflate sequentially. Compression pumps encourage the reabsorption of fluid into the venous and lymphatic systems.

The treatment modalities mentioned above are not always appropriate for every person. If your therapist thinks that they will benefit your treatment he/she will discuss these with you.

Limb positioning

You can help to prevent more swelling developing in a limb by ensuring that you use careful positioning. When resting ensure that the swollen limb is elevated to the level of your heart or slightly higher. If you have arm swelling you can rest it on a pillow when sitting or lying. Ensure that the arm is not too high as this can restrict blood flow. If you have leg swelling use a foot stool to elevate your leg when sitting and ensure that you don't cross your legs. If you are standing for a prolonged time you can try shifting your weight from one leg to the other or rise up onto your toes. Try to remember to move the swollen limb frequently to stimulate the pump action of your muscles.

Other services offered at Bupa Cromwell Hospital

Physical activity has been shown to decrease side effects of treatment, maintain strength and function during treatment, as well as improve physical well being after treatment. The most noted benefit is the fact that evidence now shows a significant decrease in the incidence of disease recurrence in cancer survivors who are physically active. The Cancer Recovery Programme ensures overall wellbeing and involves our multi-disciplinary team, including counsellors and dietitians, to advise you as needed.

- Massage therapy – massage is an ancient form of healing and helps to induce an overall feeling of relaxation on many levels including the physical, mental, spiritual and emotional.
- Counselling Service – Bupa Cromwell Hospital views counselling as an important means of support for you and your family. We offer each patient and their family eight complementary counselling sessions.
- Breast care nurse – Our breast care nurse can provide you with

information on a range of issues including bras and prosthesis.

- Outpatient physiotherapy for management of secondary problems arising after surgery or treatments for breast cancer. These may include shoulder stiffness, pain or a tight feeling in the tissues around the shoulder and breast.

Frequently asked questions

Will my diet affect my lymphoedema?

Being overweight can impact on the effectiveness of your lymphoedema treatment. It is important to eat a healthy, well balanced diet and to exercise regularly. If you need advice on your diet please discuss this with your lymphoedema therapist. Some people find that certain foods or alcohol can cause an increase in their swelling. If you feel this is happening to you it may be necessary to cut out certain foods from your diet.

The amount of fluid you drink does not have an impact on your swelling. It is important to ensure that you are drinking adequate amounts of water daily.

What should I do when I travel?

If you are travelling long distances it is advisable that you get up and move around frequently. If you are driving you may need to stop regularly. As space allows try to do some of your regular limb exercises to encourage lymph flow and drainage. When possible try to keep your limb elevated.

When flying:

- Wear your compression garments even if the swelling is under control. Do not wear a sleeve that only goes to the wrist as the hand may swell.
- A doctors certificate is useful to have with you to request a particular seat.
- Wear loose underwear and clothing.
- Watches, bracelets and jewellery should never leave indentations or red marks on the skin.
- Wear well fitting shoes with good support (for lower limb swelling).
- Keep hand luggage as light as possible.
- Ensure that you drink plenty of water. Remember that alcohol is dehydrating and even more so at 30,000 feet.

If you are travelling to hot climates you may find that the heat results in an increase in your swelling. Make sure that you continue to wear your compression sleeve during your holiday to contain the swelling, wear loose comfortable clothing, continue with your lymphoedema exercises and ensure that you have appropriate sun protection for your skin.

How much weight can I lift with my affected arm?

There is growing research into the effects of exercise on lymphoedema after treatment for breast cancer. Some of these studies look at the effect of arm exercises and arm exercises with weights on lymphoedema. If you have arm swelling you should avoid lifting heavy weights. Always start at the lowest weight and very slowly build this up provided there is no increase in your arm swelling. If you wish to have further information regarding this topic or you want to start including weights into your exercise routine please consult your therapist first as it would be beneficial for you to have an individualised programme.

Useful Websites

1. Lymphoedema Support Network (LSN):
www.lymphoedema.org/lsn
T: +44 (0)20 7351 4480 (information and support)
2. British Lymphology Society (BLS)
www.thebls.com
T: +44 (0)1242 695077
3. Cancerbackup:
www.cancerbackup.org.uk
4. Breast Cancer Care:
www.breastcancercare.org.uk
T: 0808 800 6000

Notes

Contact

If you have any questions about the information or exercises described in this leaflet please contact the Therapy department on +44 (0)20 7460 5749.

The content of this leaflet is intended for general information only and does not replace the need for personal advice from a qualified health professional.