

South Bucks Hospice 
ENHANCING QUALITY OF LIFE WITH OUTPATIENT CARE

Managing Lymphoedema

with support from South Bucks Hospice



Registered Charity No: 1128881



Content

1. An introduction to our Lymphoedema Clinic
2. What is lymphoedema?
 - The circulatory and lymphatic systems
 - The circulatory system
 - The lymphatic system
3. How is lymphoedema treated?
4. Taking care of your skin
5. Compression
 - Bandaging
 - Wraps
 - Hosiery
6. Lymphatic Drainage
 - Manual lymphatic drainage
 - Simple lymphatic drainage
7. Exercise
 - Points to remember when exercising
8. Weight
 - How can body weight impact lymphoedema?
 - Does weight loss help reduce the swollen limb?
 - Weight gain and treatment for cancer
 - What is the best way to lose weight?
9. General advice for people with lymphoedema
10. Going on holiday
11. Services on offer at South Bucks Hospice
 - Lymphoedema Support Group
 - Complementary Therapies
 - Creative Therapies
 - Emotional Support
 - Physiotherapy
 - Reviews
12. Useful names and addresses



An introduction to our Lymphoedema Clinic

South Bucks Hospice's Lymphoedema Clinic was opened in January 1997 in response to a need in the community for a service to help local people manage the condition. Since then, our passion and commitment to providing expert care has never changed.

Our lymphoedema team are highly qualified with a wealth of experience to cope with all lymphoedema needs, from diagnosis to education in skin care and maintenance of lymphoedema, plus expert knowledge of every level of compression hosiery.

Patients tell us they feel more able to take responsibility for their condition and wellbeing when given information and support alongside their treatment. So read our guide to lymphoedema and see how we can work together to help you manage your condition.

Aims of our clinic

- ▶ To provide a clear understanding of lymphoedema to patients, carers and healthcare professionals.
- ▶ To offer specialist treatment as appropriate.
- ▶ To empower patients with knowledge and skills to self-manage their condition.



What is lymphoedema?

Lymphoedema is a chronic swelling caused by a malfunction of the lymphatic system. The swelling occurs as a result of excess accumulation of lymph fluid where there is inadequate lymphatic drainage.

Any part of the body can be affected by lymphoedema but it is most common in the arms or legs.

Lymphoedema can be classified as primary or secondary.

▶ Primary lymphoedema

Primary occurs when an individual is born with an impaired lymphatic system. The swelling may be obvious at birth or may develop later in life. Primary lymphoedema may run in families or may occur as an isolated incidence.

▶ Secondary lymphoedema

Secondary can develop when there is damage to the lymphatic system caused by an external factor. This may be as a result of trauma, infection, disease, surgery or radiotherapy. Swelling can develop immediately or several years later.

The circulatory and lymphatic systems

It can be helpful to know how the lymphatic system and your blood's circulatory system work, as it will enable you to understand how swelling occurs.

The circulatory system

First, think about your heart beating. The heart pumps blood out to your arteries. This blood is full of oxygen and nutrients that keep your tissues in good condition.

The arteries become smaller and smaller until they are known as capillaries. It is at this level that the fluid part of the blood is forced out by strong pressure from the heartbeat and bathes the tissue in fluid which is rich in oxygen and nutrients.

When the cells in the tissues have used all the goodness they need, the fluid is then taken back into the circulation by the veins.

The lymphatic system

The lymphatic system works very closely with the circulatory system. At the level of the capillaries, when fluid is forced out into the tissues, not all of the fluid manages to get back into the veins. About 10% stays in the tissues.

The lymphatic system takes on the job of removing this extra fluid by way of tiny lymph vessels running through the tissue. These join together to form larger channels which then pass through the lymph nodes before re-joining the blood circulation.

The lymph nodes are an important part of the lymphatic system, as they act like 'filtering stations' by removing unwanted debris from the fluid. The fluid balance in the body is kept effectively controlled when both systems are working well together.



How is lymphoedema treated?

Lymphoedema is a permanent condition but it can usually be successfully treated and managed.

Patients tell us that they feel more able to take responsibility for their own wellbeing when given information and support alongside their treatment. The main tools of treatment offered at the clinic are known as “the four cornerstones of care”. These are skin care, compression, massage and exercise.

Essential to a positive outcome is the patient’s willingness to adapt their daily routine to include the maintenance skills taught in the clinic, enabling them to self-manage their condition.



Taking care of your skin

Personal hygiene is of great importance. Healthy skin is the best barrier that we have against infection.

Even small cracks or cuts in the skin provide an entry point for germs which could multiply quickly in the fluid that constitutes your swelling. The swollen limb is an ideal breeding ground for germs as the fluid is a little stagnant and not draining freely.

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

It is best to use a non-perfumed moisturising soap or a soap substitute such as an aqueous cream or Epaderm which is available on prescription from your GP.

Dry skin thoroughly, especially between fingers, toes and in creases where fungal infections may occur. If a fungal infection is detected it should be treated immediately. To help keep your skin supple and prevent it from becoming dry, apply a moisturising cream such as Cetaben or E45. This should be applied with gentle upward strokes starting at the top of the limb and gradually working towards your hand or foot.

It is best to apply your moisturising cream in the evening when you have removed your compression garment. This allows time for your skin to absorb the cream overnight.

It is not advisable to apply cream in the morning as you will find it more difficult to put on your garment and it can rot the fibres of your compression garment and reduce its elasticity.

If you cut, graze or burn your skin, clean it and apply antiseptic straight away. This will minimise infection. If the limb does become infected, it is known as 'cellulitis' or an 'acute inflammatory episode' (AIE). You will know this has occurred by certain signs and symptoms:

- ▶ You may experience flu-like symptoms.
- ▶ The limb may become red.
- ▶ The limb may itch.
- ▶ Swelling of the limb increases.
- ▶ The limb may become hot.
- ▶ The limb becomes painful to touch.

If this happens, you need to see your doctor as soon as possible and explain the symptoms. Your doctor will probably prescribe antibiotics to help your body fight the infection.

Rest the affected limb as much as possible and support it on a cushion.

If you wear a compression garment, take it off until the acute stage of infection has passed and the limb has reduced in size or become more comfortable.

Repeated infections can cause further damage to the lymphatic system, so it is important to try and prevent them from developing.



Compression

Compression is the basis of treatment and provides a firm outer support for the tissues. This may be in the form of bandages/wraps or a compression garment.

Aims of graduated compression:

- **To encourage movement of fluid to the root of the limb.**
- **To limit the formation of oedema.**
- **To maximise the muscle pump.**
- **To support the tissues and provide comfort.**
- **To maintain the shape of the limb.**
- **To help improve any skin problems.**

Bandaging

If bandaging is necessary as part of your treatment it will be carried out, usually in the clinic, by your therapist. Multi-layer bandaging is used to provide compression when the limb is a difficult shape or size for conventional hosiery, or if the skin is very fragile and could be damaged by putting on or removing hosiery.

An intensive course of bandaging may take between 3-5 weeks. You will be required to attend the clinic 2-3 times a week for this period.

Several layers of bandaging and foam padding will be applied to your limb to improve its shape and apply even compression. This remains in place until your next appointment when the bandages are removed, your limb washed, moisturised and re-banded.

It is advisable for you to make alternative arrangements to travel to and from the clinic during this treatment as it is difficult to drive whilst bandaged and it may invalidate your insurance.

Wraps

This method enables more self-management of problematic limb lymphoedema. You will be taught how to apply and adjust the wrap to the size and shape of your limb. Wraps can be worn day and night and in some cases are easier to apply than hosiery. You will need to ensure that you follow the guidance from your therapist about how to apply the wraps.

Hosiery

Wearing a compression garment is a very important part of your treatment. Your compression garment will have been carefully selected for you by your lymphoedema therapist.

At first the hosiery may feel strange to wear but, with perseverance, your limb will soon feel comfortable and supported in the garment.

Compression hosiery is designed to limit the formation of lymph. It provides resistance against which the muscles can pump and move lymph fluid more effectively.

You should put on your hosiery first thing in the morning and remove it last thing at night unless told otherwise by your therapist. Your hosiery may be difficult to put on but your therapist will help you to find the easiest way.

Many patients find that wearing a pair of ordinary household rubber gloves when applying hosiery makes the task a lot easier. There are also various hosiery applicators available which can be of help if you continue to have difficulty.

When you put your sleeve or stocking on, ease it up the limb a bit at a time. Make sure there are no creases or wrinkles and take care not to pull it up so high that the top rolls over. If you turn or roll the top over, it will restrict lymph drainage and cause further swelling.



Once your hosiery is in position, it should feel firm, supportive and comfortable. If you notice a change in the colour of your fingers or toes or any new numbness, tingling or pain in your limb, remove your hosiery straight away and contact your therapist.

Your hosiery should be washed at least every other day, preferably by hand, at 40 degrees or less.

Use a mild washing powder or liquid suitable for woollens or delicate fabrics.

After thorough rinsing, allow the garment to dry naturally, flat on a towel so it can reform its correct shape. Do not use a tumble dryer or iron your garment.

Lymphatic Drainage

There are two types of lymphatic drainage used in the treatment of lymphoedema. They are called Manual Lymphatic Drainage and Simple Lymphatic Drainage. Both are very gentle to receive and are very different from therapeutic or aromatherapy massage.

This form of skin stroking stimulates the superficial lymphatic system which lies just under the surface of the skin. It encourages the lymphatic vessels to drain more efficiently and can also relieve the unpleasant tight congested feeling associated with swelling. Skin stroking is carried out directly on the skin without the use of oil or cream.

Manual Lymphatic Drainage

Manual Lymphatic Drainage (MLD) is a specialised form of treatment designed to encourage lymph drainage. It involves the use of gentle, rhythmic pumping techniques to move the skin and stimulate the lymphatic system.

MLD is used in conjunction with all the other treatments described in this booklet, i.e. skin care, compression and exercise. It increases the lymphatic flow away from the swollen areas by redirecting the fluid towards fully functioning lymph nodes and vessels. It also helps to reduce the hardness (fibrosis) which can develop in the skin.

Your therapist will also work on any scars you may have during your lymphoedema treatment to break down the hard tissues. This will aid drainage and reduce tension and discomfort.

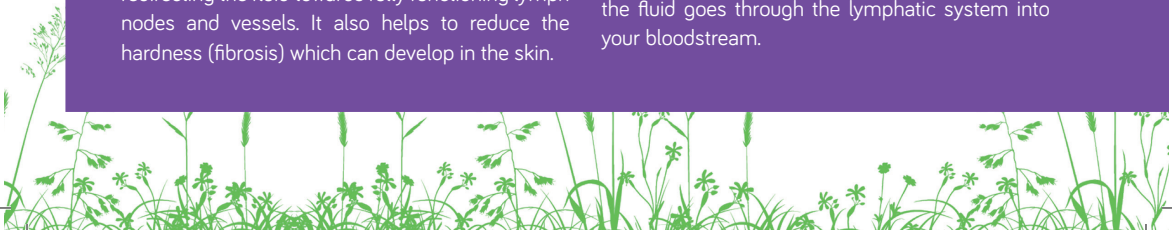
Simple Lymphatic Drainage

Simple Lymphatic Drainage (SLD) is based on the principles of Manual Lymphatic Drainage. It involves the use of basic hand movements and is designed to be easy to learn for patients and their family/carers. This is a way you can help stimulate lymph flow for yourself.

At the clinic we will teach you simple techniques to help with your particular problems.

The aim of the treatment is to move fluid from the swollen areas of your body to areas that are clear of swelling, where it can drain away more easily. The direction of the movement is away from the affected side towards the unaffected side.

With upper body swelling, this would mean directing fluid towards the unaffected armpit. With lower limb swelling, the fluid is directed towards the upper part of the body. From here the fluid goes through the lymphatic system into your bloodstream.



Exercise

Exercise is very important in the management of lymphoedema. For maximum effect, exercise wearing your compression garment and combine it with your Simple Lymphatic Drainage massage daily.

During exercise we work our body a little harder than normal. We tense and release our muscles; which is known as the 'muscle pump'. When a muscle is in a state of tension it applies pressure to the surrounding tissues and vessels, which include the superficial and deep lymphatic systems.

The muscle pump stimulates the lymphatic system to keep pace and to work at a faster rate, moving the lymph fluid along its vessels back towards the chest and away from the affected area.

When we are exercising or carrying out daily activities, the harder the muscle works then the greater the need for more nutrients and oxygen that is carried in the blood supply.

To meet this demand the body can initially divert blood from other parts of the body that are not having to work so hard. The heart is then stimulated to beat faster, thus pumping more blood to try and meet the new demands.

Lymph formation is directly proportional to the amount of blood flow. Hence the more vigorous the activity, the more lymph is produced.

This is why it is critical that you find the right level of exercise for you. You must monitor the reaction your swollen limb shows to varying levels of activity.

Likewise, there is little lymph flow in a resting limb.

Your exercise programme, designed with the help of your therapist, will assist lymphatic drainage and is an important part of managing your swollen limb. Most importantly it also:

- **Increases the range of movement at your joints.**
- **Improves muscle strength and stamina.**
- **Helps with weight control.**
- **Helps reduce the size of your swollen limb.**
- **Should be pleasurable and not a chore!**



Points to remember when exercising:

(a) Perform the exercises slowly and smoothly, with a nice even tempo. This will maximise the filling and pumping mechanism of the muscle on the lymphatic system. And, carried out little and often, it allows time for drainage to occur.

(b) Exercise should be pain free; trauma will cause an inflammatory reaction, which in turn will increase swelling.

(c) An increase in fluid stretches the skin which cannot provide the resistance needed to make the muscle pump work effectively. Compression hosiery/bandages provide a necessary resistance during light exercise to achieve the required pressure.

(d) Work on the same principles as when you carry out your Simple Lymphatic Drainage Massage. You want to enhance the flow of lymphatic fluid from the lymphatic system to the venous system by clearing the pathways that you are directing fluid into.

(e) Positioning and good posture are important. If an exercise is uncomfortable, it could mean that it is too difficult for you. Try a small movement or fewer repetitions.

(f) Remember to breathe and incorporate deep breathing into your exercise programme. This causes pressure changes in the trunk which act like a vacuum inside the rib cage helping to draw lymph fluid upwards towards the neck, where the lymphatic vessels join the venous system.

(g) Establish a routine and find the time of day that works for you! Combine your exercises with Simple Lymphatic Drainage. If you are short of time, don't just pick a few at random and speed them up!

(h) Everyone's exercise programme will be slightly different. This is due to age, medical conditions, level of fitness, interests and time.

(i) Start gently with new sports. Muscles are having to learn new skills so proceed with caution. You don't know how they are going to react!

(j) Swimming, cycling, walking, Tai Chi and Lebed are all excellent types of exercise if you have lymphoedema.

Please note: If you have any problems, for example if any exercise seems to cause an increase in swelling or pain, then stop and seek help!



Weight

How can body weight impact lymphoedema?

The answer is that no one knows exactly, but it has been suggested that part of the extra size of the swollen limb may be made up of additional fat deposited directly under the skin. It may also be that additional fat around the lymph nodes, under the arm, or in the groin, hamper drainage from the limb.

Does weight loss help reduce the swollen limb?

A study carried out at The Royal Marsden Hospital suggested that weight loss might help reduce the volume of the swollen limb. Other studies have suggested that a low fat diet may help lower the volume and alter the texture of the limb, making it softer and therefore easier to treat.



Weight gain and treatment for cancer

Some people find that they gain weight after treatment for cancer, in particular breast cancer. This may be due to the change in lifestyle or to drugs, such as Tamoxifen or those given in chemotherapy. Many women say their weight has increased after being given such medication, but it is still possible to lose weight.

What is the best way to lose weight?

It is important that any weight loss is gradual. About 1-2 lbs per week is about right. A 'crash' diet is not a good idea and the weight is more likely to be regained. If you have recently had cancer then it is best to check with your doctor as to when you should start to try to lose weight.

It is now generally agreed that a healthy diet is one that is low in fat, sugar and salt and high in dietary fibre. It should also contain sufficient protein and adequate vitamins and minerals.

General advice for people with lymphoedema

Use your limb as normally as possible, but avoid lifting heavy loads, e.g. heavy shopping, wet washing, or pushing/pulling heavy loads like a vacuum cleaner or lawn mower etc.

Avoid long periods of repetitive movement with a swollen arm, e.g. ironing, and take regular breaks.

Exercise is good for you, but avoid vigorous movements, as this can increase the swelling. If the limb starts to ache then rest with the limb elevated.

Wear loose fitting clothing, especially near the armpit or groin of the infected limb. There should be no redness or indentation when clothes are removed. Constrictive clothing or jewellery can block fluid drainage.

Keep the swollen limb clean. When washing and drying be gentle but thorough. Avoid very hot baths or showers as this may make the limb swell further.

It is important to keep the skin in good condition to prevent the risk of infection. Use a moisturiser daily to stop skin drying and cracking, e.g. Cetraben or E45 cream. The limb needs to be kept as cool as possible in hot weather. Avoid sunburn by wearing protective sun cream.

Avoid any trauma to the swollen limb wherever possible, such as knocks, cuts, burns and insect bites. When sewing use a thimble and wear gloves when gardening.





Going on holiday

If you're travelling by aeroplane you should wear your hosiery during the flight. Swelling may increase in a pressurised cabin but should go down again after the flight. If possible try to exercise your swollen limb gently every hour or so.

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

- **Shower after swimming, as both salt and chlorine can cause dryness.**
- **Use a sun block. Sit in the shade or cover up. Sunburn can result in increased swelling.**
- **Use extra moisturiser. If the swollen area is exposed to the sun it may become dryer than usual.**
- **Don't go barefoot on the beach, in the sea or around the pool if you have leg swelling. This will reduce the risk of cuts, scratches and infections.**

In hot weather swelling tends to increase. As your veins dilate to cool the body down, more fluid escapes into the tissues of the body. If possible continue to wear your hosiery. Try to stay cool and rest where possible. Any increase in swelling should go down on your return home.

Think carefully about where you are going on holiday. You may need to use an insect repellent. Remember not to have immunisations into a swollen area or any area that may be at risk of swelling. Also, take antiseptic with you in case of any damage to the skin.

Take your antibiotics with you if you are on long term treatment. If you have a history of infection talk to your doctor before going on holiday. They may suggest taking a supply of antibiotics with you.

Activity holidays can be fun but don't spoil them by overdoing an activity you are not used to. Discuss this type of holiday with your therapist before making any arrangements. Above all, enjoy yourself!



Services on offer at South Bucks Hospice

Lymphoedema Support Group

Our informal Lymphoedema Support Group takes place regularly and we sometimes have a guest speaker who gives a topical talk. We also share advice on lymphoedema so it is a great place to meet people who understand how you feel. If you wish, you can join the creative groups, who also have a guest speaker.

**Please contact the clinic on
01494 552756 for more details.**

Complementary therapies

We usually offer a course of treatments that have many benefits if you have lymphoedema. The treatments are all aimed at offering support and reducing the stress that can come with a long term condition. They can also help promote better sleep and give you a sense of calm. Please let your therapist know if you are interested in having complementary therapy. We will review how your treatments are going with you regularly. You can change your mind at anytime during the course and we will do our best to accommodate your wishes.

Creative therapies

Creative therapies can be a great way of refocusing thoughts and feelings away from your condition and give you a break while doing something you enjoy. Some of the therapies we offer are art, Mindfulness, chair yoga, horticulture and many more. Your therapist will decide if any of these will be beneficial for you and refer accordingly.

Emotional support

Living with a long term condition like lymphoedema can sometimes be overwhelming. Even if you are managing the condition successfully, looking after your emotional wellbeing is important to keeping things that way. We offer a range of emotional support services including 1-1 counselling. If you would like to find out more, please speak to your therapist.

Physiotherapy

Physiotherapy can play a huge role in your care and with gentle encouragement from our qualified physiotherapist, you can regain confidence and keep yourself mobile. Our aim is to work with you to keep you moving and doing the everyday things you need to do. Alongside 1-1 sessions we may offer gentle exercise classes which you are welcome to take part in. Please ask your therapist for dates.

Reviews

Your therapist will assess you fully and agree a treatment plan with you. Once your goals have been reached and you are confident you can maintain your own lymphoedema, you will be discharged into the care of your GP who can re-refer you to our clinic if necessary.



Useful names and addresses



The British Lymphology Society

Admin Centre
59 Brimingham Road
Lichfield,
WS13 6PG

01452 790178

www.thebls.com

A professional interest group who aim to promote knowledge of lymphoedema and its management.



Macmillan Cancer Support

89 Albert Embankment
London
SE1 7UQ

0808 808 0000

www.macmillan.org.uk

A source of support for those dealing with anything related to a cancer diagnosis.



Disabled Living Foundation

34 Chatfield Road
London
SW11 3SE

0300 999 0004

www.livingmadeeasy.org.uk

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



The Lymphoedema Support Network

St Luke's Church Crypt
121 Sydney Street
London
SW3 6NH

0207 351 4480 (information)

0207 351 0990 (administration)

E. Admin@lsn.org.uk

www.lymphoedema.org

The LSN is a national charity that provides telephone information and support to people with lymphoedema. It also produces a wide range of fact sheets and a quarterly newsletter.



MLD UK

Audroy
7 Dalys Road
Rochford
Essex
SS4 1RA

0844 800 1988

E. Admin@mlduk.org.uk

www.mlduk.org.uk

A professional body for manual lymphatic drainage therapists. It can help you to find a practitioner in your area.



South Bucks Hospice



ENHANCING QUALITY OF LIFE WITH OUTPATIENT CARE



Registered Charity No: 1128881