



**South Bucks Hospice**  
Palliative and Lymphoedema Care

A black and white photograph of an elderly couple, a man and a woman, shown in profile from the chest up. They are both smiling and looking towards the right side of the frame. The man is in the foreground, and the woman is slightly behind him.

# Managing lymphoedema

with support from South Bucks Hospice

[www.sbh.org.uk](http://www.sbh.org.uk)

Registered Charity No: 1128881

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## 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.

We receive no funding from the government budget to provide support for local people with lymphoedema and we rely entirely on generous donations from our supporters to do our work. Our clinic is the only one specialising in the treatment of the condition locally and without our help, people would be forced to seek expensive private treatment or receive no help at all.

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 to all lymphoedema patients.
- 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 tissues 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** 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** 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 of 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 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 Diprobase 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.

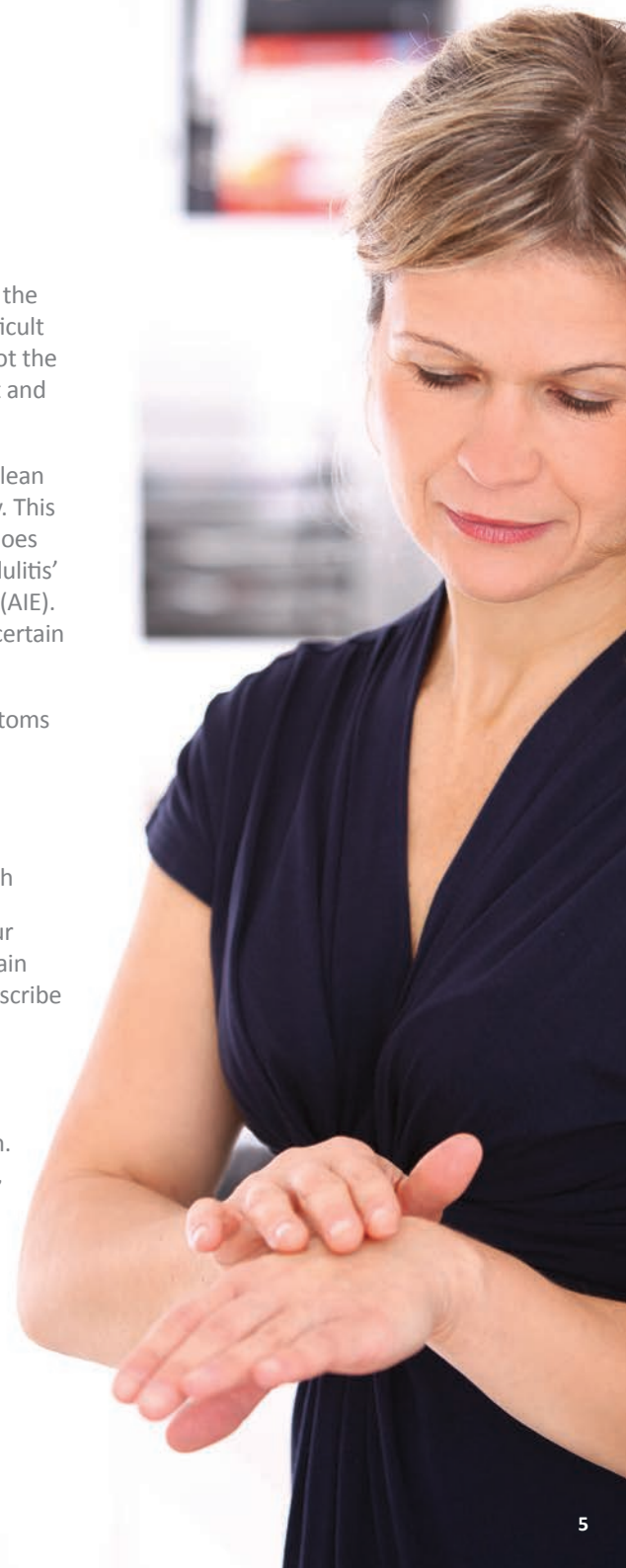
If you cut, graze or burn your skin, clean it and apply antiseptic straight away. This will minimise infection. If the limb does become infected, it is known as 'cellulitis' or an 'acute inflammatory episode' (AIE). You will know this has occurred by certain signs and symptoms:

- 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. He 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 or a compression garment.**

Aims of graduated compression:

1. To encourage movement of fluid to the root of the limb
2. To limit the formation of oedema
3. To maximise the muscle pump
4. To support the tissues and provide comfort
5. To maintain the shape of the limb
6. 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. Multiplayer 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 2 - 4 weeks. You will be required to attend the clinic 3 - 5 times a week.

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.



### 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 arm or leg 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 more effectively.

You should put on your hosiery first thing in the morning and remove it last thing at night. 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 flow 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.

## Massage

There are two types of massage 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 massage 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. The massage 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.



### Simple Lymphatic Drainage

Simple Lymphatic Drainage 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 SLD 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 or 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. 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

Most importantly it 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) Compression: 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) Order your exercises. 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 is important. If an exercise is uncomfortable, it could mean that it is too difficult for you. Try a small movement or fewer repetitions.

- (f) Breathing: 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.

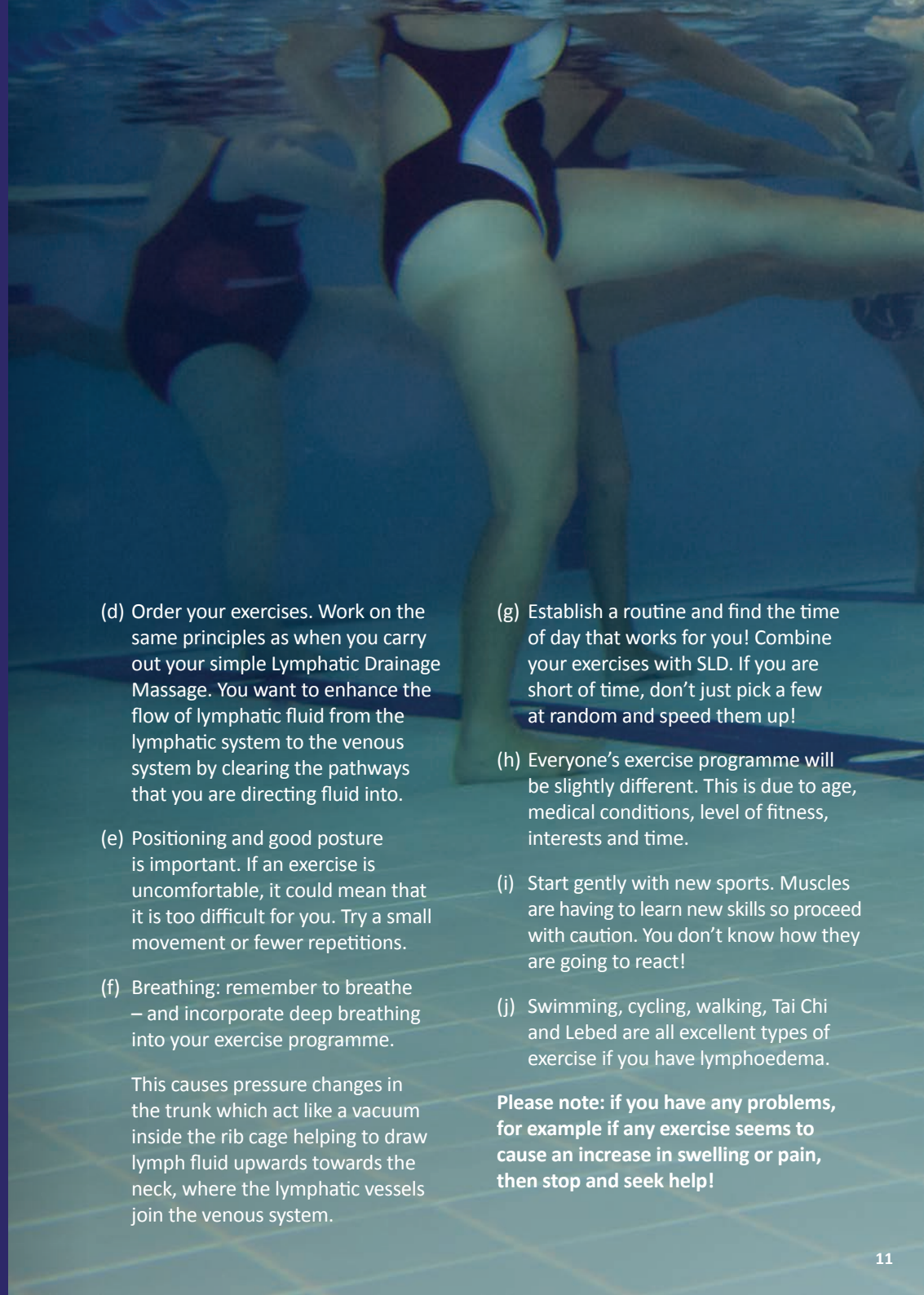
- (g) Establish a routine and find the time of day that works for you! Combine your exercises with SLD. If you are short of time, don't just pick a few at random and speed them up!

- (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!**



## Sensible eating

### 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.

Using the technique of ultrasound scanning, it is now possible to see how much fluid is beneath the skin.

### 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, possibly 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. aqueous cream 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 whenever 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 immunizations given into a swollen area or any area that may be at risk of swelling. Also take an 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. He/she 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 Edie Pusey House

### Complementary therapies

We offer a wide range of complementary therapies that have many benefits if you have lymphoedema. These include: acupuncture, aromatherapy, reflexology, reiki, beauty therapy, therapeutic touch, holistic massage, indian head massage and meditation, and relaxation class. The treatments are all aimed at offering support and reducing the stress that can come with a long term illness. They can also help promote better sleep and give you a sense of calm.

Please let your therapist know if you are interested in any of these treatments. We usually offer a course of six and will review how these 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.

The therapies we offer are: art, music\*, horticultural\*, creative writing and dream workshops\*. Please let your therapist know if you would be interested in taking part in any of these activities.

\*Available from 2015 onwards.

### Emotional support

Living with a long term condition like lymphoedema, especially if it has come after a lengthy and frightening battle, 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 and family sessions and if you would like to find out more, please speak to your therapist.

### Physiotherapy

Physio 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.

Alongside 1-1 sessions we also offer yoga and Tai Chi classes\* which you are welcome to take part in. Please ask your therapist for dates.

### Support groups

We offer a range of support groups at Edie Pusey House alongside our Lymphoedema Support Group at Cedar Barn. If you'd like to know more about what's on offer, please ask your therapist or call **01494 537775**.

Our Lymphoedema Support Group takes place quarterly and we often have a special guest who gives a topical talk. We also share advice on lymphoedema and it's a great place to meet people who understand how you feel. The group is informal and we enjoy refreshments and a raffle at each meeting. New members are also welcome to bring a friend along. You can find meeting dates for the group on the inside back cover.

## Useful names and addresses

### British Lymphology Society

#### Admin Centre

PO Box 196  
Shoreham  
Kent  
TN13 1LZ  
t: 01959 525524  
[www.lymphoedema.org/bls](http://www.lymphoedema.org/bls)

The BLS is a professional interest group who aim to promote knowledge of lymphoedema and its management.

### Lymphoedema Support Network

St Luke's crypt  
Sydney Street  
London  
SW3 6NH  
t: 0207 351 4480  
[www.lymphoedema.org/lsn](http://www.lymphoedema.org/lsn)

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.

### Cancerbackup

3 Bath Place  
Rivington Street  
London  
EC2A 3JR  
t: 0207 696 9003  
[www.cancerbackup.org.uk](http://www.cancerbackup.org.uk)

### MLD UK

PO Box 14491  
Glenrothes  
Fife  
KY6 3YE  
t: 01592 748008  
[www.mlduk.org.uk](http://www.mlduk.org.uk)

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

### Disabled Living Foundation

380-384 Harrow Road  
London  
W9 2HU  
t: 0845 130 9177 (local rate)  
[www.dlf.org.uk](http://www.dlf.org.uk)

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



### APPOINTMENT CARD



Date:

Time:

Therapist:

### LYMPHOEDEMA SUPPORT GROUP MEETINGS

Date:

Time:

Location:





# South Bucks Hospice

Palliative and Lymphoedema Care



## Lymphoedema

Cedar Barn, Cedar Avenue, Hazlemere, High Wycombe,  
Bucks HP15 7DW **t:** 01494 717050 **e:** [info@sbhospice.org.uk](mailto:info@sbhospice.org.uk)

## Palliative Care

Edie Pusey House, 9a Amersham Road, High Wycombe,  
Bucks HP13 6PN **t:** 01494 537775 **e:** [info@sbhospice.org.uk](mailto:info@sbhospice.org.uk)

## Fundraising

9b Amersham Road, High Wycombe, Bucks HP13 6PN  
**t:** 01494 464045 **e:** [fundraising@sbhospice.org.uk](mailto:fundraising@sbhospice.org.uk)

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

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**Affirming life with palliative support**