

LSN

THE LYMPHOEDEMA
SUPPORT NETWORK

because lymphoedema matters



RECREATIONAL EXERCISE WITH LYMPHOEDEMA

This information has been produced and verified by accepted experts in their field. It reflects current best practice and evidence based research where appropriate. It has been designed to assist you in managing your condition and is not intended to replace advice you may receive from your healthcare practitioner. If you or your healthcare practitioner would like to ask any questions or require details of the research used to develop this information, please contact the Lymphoedema Support Network on 020 7351 4480.

Introduction

'I have been diagnosed with lymphoedema and have been given special exercises to do. Does this mean that I have to stop my usual sport or stop trying new ones?'

This is a question that people with lymphoedema frequently ask. As yet, evidence on the effect of exercise for lymphoedema patients is limited; however, studies agree that exercise is helpful when it is **gradually** increased over time. This fact sheet also includes feedback from LSN members about their experiences of using exercise and what has benefited them.

The aim of this guidance is to provide some general information on recreational exercise and how it can be beneficial. This information may help you to identify a useful and enjoyable activity. It is important that you start exercises for a short period and gradually build up your strength and endurance. You can also use this guidance if you are resuming an activity that you have not done for some time. However, this fact sheet does not include specific exercises that are recommended as part of your lymphoedema treatment; your lymphoedema clinic will be able to provide you with an exercise programme that is specific and appropriate to your needs.

Why is exercise important?

Regular exercise will help you to control your swelling and can also make you feel good as it increases your endorphins. It will help you to keep your joints flexible and keep the muscles well toned. It can also relieve pain and discomfort due to joint stiffness and lack of mobility.

A gradual, steady increase in regular exercise will ensure that your body works efficiently. It also helps to reduce tiredness, stress and anxiety, helps keep your bones and heart in good condition and helps keep weight within normal limits. If you have lymphoedema, exercise also helps to:

- improve lymph drainage by working your muscles
- prevents joint/muscle stiffness
- improve your posture, balance and gait

What happens when you exercise?

When you exercise, your heartbeat gets stronger and faster, sending extra oxygen and nutrients to the working muscles. During movement, the muscles produce a pumping action on the blood and lymph vessels, helping them to send fluid and waste products away from the tissues and back into the general circulatory system for processing and removal. As your breathing becomes heavier, the movements of your chest stimulate and improve fluid flow through the veins and lymph vessels.

Why exercise when you have lymphoedema?

Studies have shown that muscle activity is extremely important when the lymphatic system is not working correctly so any extra movement and exercise you can do will be helpful in reducing your swelling (especially when compression is worn at the same time.) However, exercise is also a way to increase the circulation of a special hormone, called endorphin, in the bloodstream. This endorphin creates a 'feel good' effect and can help to overcome any negative or sad feelings and emotions that can often accompany lymphoedema.

Wearing a compression sleeve or stocking when you exercise is important and will help to control the swelling more effectively, because the firm support offered by the compression garment assists the muscles to pump more efficiently. However, it is not as necessary to wear garments when swimming, as the water provides the same sort of support as garments. Water also provides resistance to movement which makes the muscles work harder – so swimming/exercise in water is especially good for people with lymphoedema. Some people also choose to wear their garments in the water (especially during hot weather) – this will help to enhance the effects of the exercise.

You can and should exercise when you are wearing Multi-layer Lymphoedema Bandaging (MLLB) during intensive treatment. Lymphoedema bandages are made of a firm material that will help the muscles to pump the lymph away from the swollen area. Although the bandages can be bulky, there are still exercises that you can do. For example, if you have leg swelling, you can build up a walking programme. Walking on the spot is just as helpful. If your arm is swollen, you can still move your shoulder and use your other arm to help with stretching exercises. You can also bend and straighten your elbow and stretch out your fingers and then make a fist.

Remember, the sort of exercise you can do will depend on your age, inclination and general fitness. If 'keep-fit' exercises are not for you, ask your lymphoedema practitioner for a daily home exercise programme that could help to keep the swollen limb under control.

Exercises have a more effective pumping effect when they are done slowly and smoothly, so make sure you have time available so that you do not have to rush through them.

There are two self-management DVDs available from the LSN entitled 'Self Management Techniques for Arm/Leg Lymphoedema' which include a section on exercise. A booklet entitled 'Lymphoedema – Advice on self-management and treatment' (third edition) written by Professor Peter Mortimer and Dr. Jacquelyne Todd, also has a section on exercise and both of these are available from the LSN.

What to watch out for

- Don't overstrain yourself and only exercise to your level of endurance. As you become fitter, you will be able to do more and still feel comfortable.
- Do not push yourself to continue with an exercise that causes any pain. Stay within the pain-free range. If movement is tight, stretch your limb slowly and gently.
- Do not exercise when you are being treated for a skin infection (cellulitis) as this will spread the infection and make you feel more poorly. Don't exercise if you are feeling unwell with 'flu'-like symptoms as you need your energy to get better.
- If you have had surgery near the lymph nodes, check with your lymphoedema practitioner when you can safely start a new exercise regime.
- If planning to work out with a programme of exercises, you will need to seek advice from your fitness instructor or a physiotherapist. You will need a suitable 'warm up' and 'cool down' programme to help reduce any muscle and joint strain.
- 'Cool down' exercises will help to prevent the build-up of fluid and waste products in the tissues and lactic acid in the muscles after exercise that puts more strain on the lymph drainage system.
- Deep breathing before and at the end of exercising helps you to get a good supply of oxygen and to help you to relax after exercises. Ensure that you have sufficient rest periods between exercises and don't overdo it!
- If you go to a gym class or activity, let your instructor know that you have lymphoedema and why you may not be able to do all the exercises.
- Use common sense! If something looks too difficult and you are not sure it is a good idea, you are probably right. If in doubt, ask a healthcare professional first.
- Do be careful about your posture when you exercise. When possible, keep your shoulders back, your chin tucked in and stand tall!
- Wear your compression garment when exercising and keep it on for at least an hour afterwards. If you find that your limb is swelling more after the exercise, it may mean that you have done too much, so cut back a little bit the next time.

Ask for advice from your lymphoedema practitioner, a chartered physiotherapist or your doctor, if:

- Your limb suddenly becomes more swollen or heavy.
- You have an inflammatory joint condition such as arthritis.
- Your medical history includes a condition that may prevent you from fully exercising.
- You find exercising difficult or painful.

Helping you start

- Find an activity you enjoy – you're more likely to keep it up.
- If you try one type of exercise and don't like it, try something else; there are plenty of different activities available for you to try. Contact your local council to see what activities are provided in the parks or leisure centres or speak to your GP to see if they can organise exercise on referral.
- Exercise does not have to be gym based. You can dance, try a Zumba class or even use a Wii. These computer games are great fun and all the family can be involved (especially useful if you have children or grandchildren).
- Start gently, with plenty of rest periods.
- If you haven't exercised for a long time, start with short sessions – only 10 or 15 minutes.
- If you go to the gym, start with a routine that does not involve using heavy weights with your affected limb. As you start to feel stronger, you can gradually increase the number of times you repeat the exercises and introduce light weights. In time, you may be able to increase the level of exercise and the weights that you use. Gradually build up the time spent on a static cycle, cross trainer or rowing machine.
- Keep your old compression garments. They may be suitable for exercising in or for using over the top of your usual sleeve or stocking to get some extra support. Wash your garments after each use.
- Exercising in water is very helpful, even if you can't swim (walking in the water is very helpful for leg swelling). The water takes the weight off your joints and the water pressure helps to support your swollen limb. Aqua aerobics can be great fun and very beneficial – ask for details at your local health centre.

Exercises and activities that others have found useful

Swimming, water activities and aqua aerobics are by far the most popular activities. In water, your limb is supported and you do not need to wear your garment if you don't wish to do so, but make sure you put it on as soon as possible when you are dry. Because the exercise feels easier in the water, you need to be careful not to overdo these sessions, especially at first. Gradually, you could build up to using floats to make the exercises harder. An instructor or physiotherapist could show you how.

Keep your swollen limb in the water for most of the time – the breast stroke is a good exercise to start with if you are comfortable with swimming.

Make sure that you shower thoroughly to remove the chlorine from skin and be extra thorough when applying your moisturising cream later on. Wear protective footwear in the pool and around the pool sides to reduce the risk of fungal infections like athlete's foot.

Golf and racquet sports can be great fun and can be done with other people. If your arm or hand becomes more swollen, you may be using it to grip for too long. Keep moving your fingers as frequently as you can and release your grip on the racquet between shots. Make sure you wear your compression garment and if necessary, wear extra support such as an old sleeve or stocking on top of your usual garment. If your hand is swelling, a compression glove can help. But remember, be careful of repeated swing movements and release your grip on the handle whenever possible.

Cycling is a useful way of exercising your legs, and seeing new places. If you have leg swelling, wear firm compression stockings and start with short rides on level ground. If you have arm swelling, release your grip on the handlebar and move your shoulder as well as squeezing and stretching your fingers as much as possible, even if this means taking frequent rests at first. This will aid lymph drainage. Electric bikes have become much more popular recently and although they can take the hard work out of cycling, you still need to pedal, so they are excellent ways of keeping you fit and feeling good.

Walking provides a pleasurable outdoor activity that you can enjoy with or without other people. Walking groups are available which will offer variety and guidance and can also help to provide company and support – especially if you live alone.

If you have arm swelling, find a jacket with deep pockets that you can rest your arm in. Keep something like a pebble, sponge or piece of plasticine in your pocket so that you can exercise your hand and fingers as you walk along. The LSN has a stress ball which can be intermittently squeezed as you walk to stimulate the lymph system.

If you have leg swelling, wear supportive footwear and good quality walking socks. Gradually build up the speed and length of time you are out walking.

Running can put an extra strain on your leg(s) if you have lower limb swelling, so start very cautiously and build up gradually. You will need strong supportive hosiery for this type of activity and may also find self-bandaging helpful to offer extra support to your swollen leg(s). Ask your therapist about this if you are a keen runner. Running can also affect arm lymphoedema. Always wear your sleeve to prevent further arm swelling as sometimes gravity or holding your arm in one position can aggravate the swelling. Occasional hand pumping can also help keep the lymph system draining more efficiently.

Don't forget to protect your skin by applying sunscreen when performing an outside activity. Whenever you can, walk and rest in the shade and make sure that you drink plenty of water to stay well hydrated.

Yoga or T'ai Chi

These types of exercises focus on breathing and relaxation, which will be of great benefit to both the way you feel, as well as helping you control your lymphoedema. As the exercises are usually slow and rhythmical, they are very similar to the exercises given in lymphoedema programmes. Be careful not to over stretch or to hold the swollen limb in one position for any length of time.

Gym

Gentle activities such as static cycling, walking on a treadmill and exercise involving regular movement can be helpful. If you have arm swelling, don't grip on to a piece of equipment such as a stepper for longer than five minutes at first without resting your hand and moving your hand position. Squeeze and stretch out your fingers regularly to stimulate the lymph circulation.

Do not start with heavy weights if you have arm swelling as they can make the swelling worse. Always start with the lowest weight possible (e.g. half kilogram weights) and build up very slowly if there are no increases in limb size. Some lymphoedema patients have found the Power Plate useful. This is an oscillator/vibrating type of machine that shakes your body all over. They can be found in gyms or beauty clinics.

Don't forget – there are many different activities to try which may include salsa, line dancing, surfboarding, kayaking, snow boarding or horse riding! In each case, the most important thing is to know your limits. If your swelling consistently increases after an activity, this may mean that it is not for you at the moment. However, if the activity is something you really enjoy, discuss it with your lymphoedema practitioner who may be able to suggest some stronger garments or a way of bandaging your limb. Do not give up or get disheartened – there is always an alternative!

Note: Chi machines and circulation boosters, for example, can offer help for those who have difficulty actively moving their limbs (e.g. people who have weak or paralysed limbs). These machines are a type of passive exerciser that gives stress-free exercise while the user is lying or sitting down.

New research on exercise

There are some useful articles about exercise and lymphoedema after breast cancer treatment. You can download summaries of these on the internet. These are available by carrying out a search on **www.pubmed.gov**

Some more recent studies are investigating the effect of more vigorous exercise in women with breast cancer related lymphoedema. These were mainly exploratory studies carried out by experienced professionals who could supervise the exercises. The early results indicated that more vigorous activity was helpful and did not cause any harmful effect. More work is needed in this field so that the effects of exercise are more fully understood. However, the information that is available so far demonstrates that recreational exercise will help you in many different ways, not least:

- By improving your general well being (by reducing tiredness, stress and anxiety)
- By helping you to keep weight within normal limits
- By helping to look after your bones and heart
- And can, more importantly, also help to improve/reduce your lymphoedema.

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1. Member of original contributors' panel
2. Member of 03/2012 contributors' review panel

This information was revised in 03/2012. It will next be reviewed in 03/2014 or before, should the LSN become aware of significant changes in practice.

LYMPHOEDEMA IS THE SWELLING OF THE LIMBS AND BODY DUE TO THE ACCUMULATION OF LYMPH.

Lymphoedema affects at least 100,000 men, women and children in the UK causing swelling of the limbs or body and an increased risk of infection (cellulitis). However, it remains an underestimated health problem and is little known or understood by many medical practitioners.

The Lymphatic System

Lymph is a colourless fluid which forms in the body. It normally drains back into the blood circulation through a network of vessels and nodes. Lymph nodes act as filter stations and they play an important part in the body's defence against infection, by removing excess protein, cells (which may include cancer cells) and micro-organisms.

Why does lymphoedema occur?

If the drainage routes through the lymphatic system become blocked or damaged, lymph accumulates in the tissues and swelling (oedema) occurs. Unlike other oedemas, lymphoedema leads to changes in the tissues such as fibrosis (hardness) and an increased risk of infection. The swelling can then become even more difficult to control.

Primary and Secondary Lymphoedema

Primary Lymphoedema develops as a result of a fault within the lymphatic system itself - usually as a result of genetic underdevelopment or weakness of the lymph conducting pathways. It can affect children and men or women at any age.

Secondary Lymphoedema is the result of damage to lymphatic pathways. This maybe the result of treatment for cancer following surgery or radiotherapy. It can also occur as a result of infection, severe injury, burns, or any other trauma that can damage the lymphatic nodes/vessels. It can also arise as a result of the venous system not working efficiently (i.e. those who have had a deep vein thrombosis (DVT), varicose veins or varicose ulcers). Those patients suffering from lack of muscle movement (i.e. those suffering from a stroke or Multiple Sclerosis) may also be at risk.

EARLY DIAGNOSIS AND EARLY TREATMENT ARE VITAL TO CONTROL LYMPHOEDEMA.

Become a member of the LSN – see next page.

The LSN is a registered charity founded in 1991. It provides vital information and support for people with lymphoedema, while working towards the availability of better national resources for lymphoedema treatment.

What the LSN offers to members:

- Telephone information and support line
- Quarterly newsletters containing current information on lymphoedema, research and treatment
- A wide range of 'gold standard' fact sheets
- A frequently updated website
- Self-help DVDs
- School packs

The LSN relies solely on membership subscriptions and donations. Please help us to continue our vital work by becoming a member and/or making a donation.

APPLICATION FOR MEMBERSHIP

Mr, Mrs, Miss, Ms. SURNAME _____

First names _____

Address _____

_____ Post Code _____

Telephone (Home) _____

(Work) _____

- I have Lymphoedema
- I am a Health Care Professional
- Other (please specify) _____

I would like to join the LSN and enclose a cheque made payable to the LSN for _____

Annual UK subscription £15.00

Annual overseas subscription £30.00

Donation to support the work of the LSN of _____

Total _____

Please send to:
The Lymphoedema Support Network
St Luke's Crypt, Sydney Street, London SW3 6NH

Fact sheets available:

Breast and truncal oedema
Coping with lymphoedema following a mastectomy or lumpectomy
Management of cellulitis in lymphoedema
Manual Lymphatic Drainage for people with lymphoedema
Skin care for people with lymphoedema
Holidays and travel for people with lymphoedema
The use of compression garments in lymphoedema management
Reducing the risk of developing lower limb lymphoedema
Reducing the risk of upper limb lymphoedema



For information and help, please contact

The Lymphoedema Support Network
St Luke's Crypt, Sydney Street, London SW3 6NH

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