

Macmillan Lymphoedema Project for Scotland



Top Tips for the Self Management of Lymphoedema – A Guide

Co-Created by People Living with Lymphoedema

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Background

Long term conditions are conditions that generally last a year or longer, and may impact upon a person's life. People living with long term conditions may require ongoing care and support from others. Long term conditions are usually, but not necessarily, health conditions and include learning and physical disabilities. Lymphoedema is a long term condition.

In 2008, the ALLIANCE and the Scottish Government launched 'Gaun Yersel' - The Self Management Strategy for Long Term Conditions in Scotland. This recognised both the considerable contribution self management can make to someone's life and of self management as a movement driven not by policy makers but, by people themselves. Self management is the key to meeting the growing challenge of long term conditions and this strategy harnessed the motivation, commitment and creativity of those at the heart of this agenda – people who themselves live with long term conditions.

The ALLIANCE's vision is "for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre".

The Self Management Strategy is informed by the lived experiences of people with long term conditions.

The Strategy called for:

- People to have more access to high quality information about their condition and its impact on their life.
- People to have more access to support including peer support. Increased provision of emotional and mental health support for people with long term physical conditions.
- A change in culture so that people - those receiving and those delivering services - have the confidence and capacity to work together as partners.
- Better partnership working by NHS, voluntary sector and local authorities.

Self Management is part of the Person-centred Ambition of the NHS Scotland Quality Strategy.

My Condition, My Terms, My Life

In October 2010 the ALLIANCE launched the My Condition, My Terms, My Life campaign to share the message that living with a long term condition does not stop you being in charge of your own life.

The campaign is designed to:

- help improve public understanding of what self management means for people living with long term conditions, and
- encourage people living with long term conditions, and the people who support them, to adopt a self management approach



A dedicated website offers further information on general self-management of long term conditions, why self-management is valuable to people and how it can help you on a day-to-day basis. There are also a number of resources available which have been funded by the Self Management Fund. There are lists of support groups available, details of events, news, and real life stories available on the site. There is also a professional resources section which contains advice for people involved in the care of those with long term conditions.

For more information on the campaign and self-management itself, please visit the website <http://www.myconditionmylife.org/>

The Haven, Blantyre, received a Self Management Fund allocation from The ALLIANCE to develop a Lymphoedema Self Management Course in their local area. The six-week course supports people living with lymphoedema, or at risk of developing lymphoedema. It aims to increase participants knowledge and understanding of lymphoedema, improve their emotional wellbeing, confidence and self-esteem and enable them to develop skills and strategies to most effectively self manage their condition.



The Macmillan Lymphoedema Project for Scotland

The Macmillan Lymphoedema Project for Scotland is a project that is funded by Macmillan Cancer Support and hosted by the ALLIANCE (Health and Social Care Alliance Scotland). The project aims to develop recommendations for the equitable care and support of people living with primary and secondary, cancer and non-cancer related lymphoedema in Scotland.

A key aspect of lymphoedema care is self management and the following resources have been co-produced by professionals, people living with lymphedema and their carers to provide condition specific, easily understandable, useful and relevant information for people living with the condition and professionals involved in their care. This Guide is part of the work of the Macmillan Lymphoedema Project for Scotland.

“I’ve had a lumpectomy, a mastectomy,
chemotherapy and radiotherapy.
Lymphoedema is the worst part!”

View of a participant at the Glasgow Event

ALISS

The ALISS (Access to Local Information to Support Self Management) is an electronic resource currently being developed based in the ALLIANCE. The main focus of the ALISS project is to make local information about Self Management support easy to find.

ALISS links up currently available online local information about self management support in Scotland. All you need to do is enter the website and put in the city/town name where you live and a map will appear containing all of the self management support available locally. The site is updated by ALLIANCE members, health professionals and those living with long term conditions. For more information around ALISS visit <http://www.aliss.org/>

Introduction

The following information has been adapted from resources produced by Macmillan Cancer Support, the Lymphoedema Support Network, the British Lymphology Society and the Long Term Conditions Alliance 'My Condition, My Terms, My Life' campaign.

This Guide is for use by people with lymphoedema and also a useful resource for health and social care providers involved in lymphoedema care.

This Guide has been co-produced with people who live with lymphoedema and their carers. To inform the development of this Guide two events were held as part of BLS Lymphoedema Awareness Week (10-14 September 2012). The first was held in Inverness (hosted by our colleagues from the NHS Highland Lymphoedema Self Management Project) and the second in Glasgow at the ALLIANCE offices and a number of additional participants responded by post. Existing self management information was reviewed, amendments suggested and ideas captured in order to develop a fully comprehensive, practical guide for self-management. We are deeply grateful to everyone who gave their time and contributed their ideas to develop the Guide.

Additional comments were captured as part of the events which centred on education to care professionals, public awareness, diagnosis, on-going management and equity of treatment. These issues will be addressed as part of the further work of the Macmillan National Lymphoedema Project for Scotland.

'Top tips' are intended to provide you with an understanding of what is possible in terms of self-management. However, it is important to remember the following general self-management rules:-

- Ask questions when you talk to someone about your condition. It may be useful to prepare a list of questions before you go for your appointment.
- Don't be afraid to ask for help.
- Find out as much as you can about lymphoedema, its ups and downs and how this may impact on your life.
- Try to be realistic and achievable in the goals you set for yourself.
- Talk about your condition, try to remain positive and communicate with other people.
- Find other people who may be going through similar experiences, it often helps to share ideas and experiences.

Lymphoedema is a condition that never goes away, that is why it important to stay involved in your lymphoedema care. Keeping up with all the precautions and treatments advised by your specialist practitioner can be demanding and you may need extra support.

Remember, there isn't a one-size-fits-all model for self-management. It has to be tailored to your individual needs, circumstances, other underlying medical conditions, ability and personal wishes.



What is Self Management?

The terms self-care and self-management are often used interchangeably. The ALLIANCE uses the following to clarify these terms:

- Self care is what each person does on an everyday basis. This is often compromised for a person living their life with long term conditions.
- Self management is the process each person develops to manage their conditions.
- Support for self care and self management is the responsibility of health and social care providers and unpaid carers.

Self management puts people living with long term conditions' in the driving seat'. It supports and encourages people to access information and to develop skills that will enable them to live their lives on their terms.

Self management is not a replacement for services. It's about working with people who can provide the right support at the right time to enable individuals to choose how they want to live with a long term condition(s).

Self management does not mean having to manage alone without support. It enables people to make informed choices about how and when to draw on different kinds of support.

Self management is not an individual action, specific treatment or service. It has to be tailored to each person's needs, circumstances and wishes. It supports people to live full lives while dealing with the reality of living with a long term condition(s). It is important to recognise 'what's best for you'.

LYMPHOEDEMA – An Overview

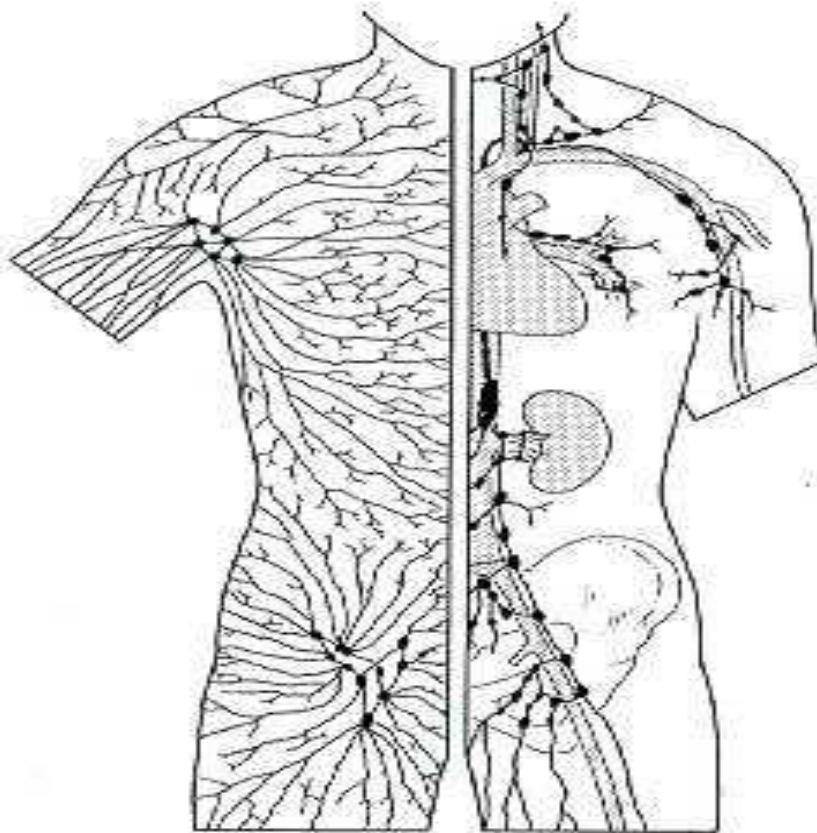
What is the Lymphatic System?

The lymphatic system is made up of groups of lymph nodes throughout the body, which are connected by a network of lymph vessels.

The lymphatic system:

- acts as a one-way drainage system transporting extra fluid from body tissues into the blood circulation
- contains white blood cells called lymphocytes, which fight infection
- gets rid of waste products produced by cells.

Diagram of superficial and deep lymphatic system obtained from the School of Nursing and Health Care, University of Glasgow

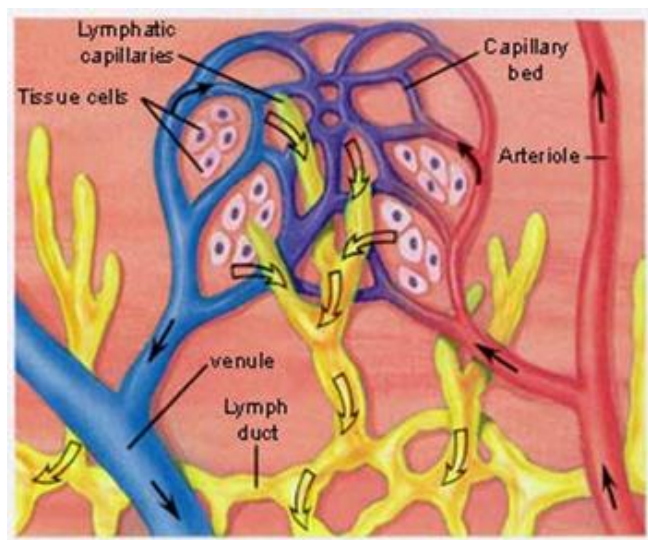


What is Lymph fluid?

This is the liquid that flows through the lymph vessels and the lymph nodes.

What are Lymph vessels?

These are tiny channels which usually lie just under the skin. They can be easily damaged if the skin is broken. Small lymph vessels join together to form larger lymph vessels, which pass through a number of lymph nodes.



What are Lymph nodes?

Lymph nodes are found throughout the body, but mainly in the neck, armpit, groin and tummy (abdomen). Lymph nodes contain white blood cells (lymphocytes), which attack and break down bacteria or other harmful cells. Waste products and the destroyed bacteria are then carried in the lymph fluid into the bloodstream and are disposed of with other body waste.

Lymph nodes vary in size; some are as small as a pinhead and others are about the size of a baked bean. The number of lymph nodes in the body varies from person to person. Different parts of the body also have different numbers of nodes; in the armpit, for example, there are about 15-30 small nodes.

Lymph fluid flows through the lymph nodes, which act as a filter by destroying or trapping anything harmful that the body doesn't need. This includes bacteria, viruses, damaged cells or cancer cells.

Sometimes the lymph nodes trap bacteria or viruses that they can't destroy immediately. The lymph node may then swell, and become tender and sore to touch. This is usually the sign of an infection which may need treatment with antibiotics.

Sometimes cancer cells spread into the lymph nodes from a cancer in another part of the body. It's also possible for a cancer to start in the lymph nodes themselves (lymphomas). If this happens, the lymph nodes become swollen but are usually painless.

There are different causes for swollen lymph nodes, but if you do develop a painless, swollen lymph node it's important to have it checked by your GP.

A more detailed overview of the lymphatic system can be found in Appendix 1 at the end of this Guide.





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Tip 1 – Identifying the Early Signs of Lymphoedema

The symptoms of lymphoedema include:

Swelling - your clothing, shoes or jewellery (rings or watches) may feel tighter than usual. This may be the first sign you notice before you even see any swelling. Alternatively, the swelling may quickly appear for no apparent reason.

For primary lymphoedema swelling can begin at any time in any part of the body eg. following an insect sting or injury. For secondary lymphoedema, swelling may occur following surgery/investigations close to the site of the procedure eg. chest/trunk, arm, leg, genitals, head and neck.

Change in feeling - the limb or area affected may feel heavy, weak, tight, full, numb, twitching or stiff, or have a feeling of pins and needles.

Skin changes - the skin in the area may feel tight, stretched and sometimes the texture can feel thicker. Skin may also be dry, flaky, rough or scaly.

Early signs of genital lymphoedema may be the development of small lymph blisters which start off very small but get larger as time goes on. These can easily become infected.

Aching - in the affected area, feeling as though you have a bruise.

The symptoms of lymphoedema vary depending on whether it is mild, moderate or severe. At first, the swelling may not be very noticeable. There may be swelling in the tissue, and soft and gentle pressure might leave a mark or indentation on the skin (pitting oedema).

Not everyone is told of the chances of developing lymphoedema before swelling starts. If you have **any** signs or symptoms of lymphoedema, you should contact your hospital doctor, specialist nurse, physiotherapist or GP for advice. Don't wait to see if it goes away! Have it checked as soon as possible. Treatment can improve lymphoedema and the earlier it's started the more straightforward and successful it's likely to be.

Lymphoedema can develop at any time, sometimes a number of years after you have had investigations, surgery or treatment.

I had a sore elbow, but it wasn't swollen. Then the feeling changed to something "popping" like a burst blood vessel. Then the area became swollen. (Comment from Glasgow Event)



Photograph reproduced courtesy of Free Digital Photos.net

Tip 2 – Understand Your Feelings

Don't worry too much if you have negative feelings from time to time. These are usually worse following diagnosis but often get easier to cope with as your lymphoedema improves/settles and you get used to managing it.

Feeling self-conscious

You may feel self-conscious or embarrassed about the effects of lymphoedema on your body (body image) and worry that people are looking at you. How you look doesn't define who you are and your family and friends will see you for who you are as a person.

Although it can take time, lymphoedema affected limbs can be reduced and you'll usually find that you become less self-conscious about it. Wearing loose clothes, which are still fashionable, may help you to cope with the changes in your body.

You might find it helpful to prepare a way of explaining lymphoedema to people who may ask questions or comment about it. People who have lymphoedema or your specialist lymphoedema practitioner may be able to help you with this, but it's up to you how much you want to say about your condition.

Feeling responsible

Some people worry that there's something they could have done to prevent lymphoedema. Little is known about the triggers for lymphoedema in certain people. It's important to remember that it is **not your fault**.

Feeling angry and resentful

It's natural to feel angry and resentful at having lymphoedema. You may feel resentful about the extra effort and time you need to take care of yourself and managing lymphoedema, when others are free to get on with their lives. Try not to bottle up your feelings - talk to the people close to you, or your specialist lymphoedema practitioner or GP, about how you feel. They can help, or signpost you to professionals or peers, who will be able to give you the practical and emotional support you need. Talking and

meeting others with lymphoedema may be helpful and there may be a peer support group near to where you live.

As the lymphoedema becomes more controlled you will usually find that you feel more able to do the things you enjoy. Or you may find new activities to replace the things that are now harder to do.

Feeling low

Lymphoedema is an ongoing problem and at times you may feel low about your situation. This is a perfectly normal reaction, although the severity differs from person to person.

Try to let your family and friends know how you are feeling so they can support you. Talking about your feelings isn't always easy. It's important to be kind to yourself and not feel guilty about needing extra help to deal with your emotions.

For some people, feelings of anxiety and sadness don't improve. If you think you may be becoming depressed, talk to your doctor or nurse as soon as possible. They will be able to refer you to a counsellor or psychologist for specialist help if they feel this is required.

Some of the emotional signs of depression to look out for include:

- feeling low in mood most, or all, of the time
- having no interest in, or enjoyment from, things you usually enjoy
- feeling helpless or hopeless
- feeling numb, overwhelmed or out of control
- constantly focusing on worries
- eating more
- decreased motivation to do things you usually do
- feeling afraid eg. worried about infections, increased swelling, what people think.

There are ways which you can help yourself overcome low mood. Some people find using complementary therapies, taking regular exercise or setting small achievable goals will build and maintain a positive mental attitude.

Talk to someone or share your experience

Talking about your situation can help to reduce feelings of stress, anxiety and isolation. There are lots of different ways we can communicate, and these can all help people feel less alone.

Try not to 'bottle up' your feelings. Self-help or support groups offer a chance to talk to other people who may be in a similar situation and facing the same challenges as you. Joining a group can be helpful if you live alone, or don't feel able to talk about your feelings with people around you. However, not everyone finds talking in a group easy, so it might not be for you. Try going along to see what the group session is like before you decide.

The **Lymphoedema Support Network** promotes the formation of self-help support groups around the country and information can be obtained from them on the support available in Scotland. Your GP may know of self-help options available in your local area, which may include self-help for younger people who need access to specialist and age specific advice.

Additional suggestions from participants at Events

Recognise when you need help and ask; feeling frustrated with daily life eg. peeling potatoes; having some 'me time' and making space for myself; if your movement is affected then your mood and ability to stay active are affected too; you need someone who understands what lymphoedema feels like; and talking to others prevents you becoming isolated.

Listening to Uplifting Music Boosts My Spirits

Comment from Inverness Event



Tip 2 "gave me permission to have emotions about my lymphoedema and how it affects me, the person, and how I do recognise how 'lucky' I am to be alive to moan about it. I do have to live with it though." Comment from postal respoondee



Photograph reproduced courtesy of Free Digital

Tip 3 – Look After Your Skin

Looking after the skin in the area that is at risk of lymphoedema is very important. Keeping skin clean and well moisturised reduces the risk of inflammation or getting a skin infection. There is also less risk of getting cracks or cuts in skin that is well moisturised and supple. Any break in the skin can make you more likely to get an infection in that area.

It's also important to protect the area that is at risk by¹:

- Wearing rubber gloves when doing household tasks, gardening, DIY or when handling animals. People with lymphoedema suggested wearing disposable gloves in the kitchen (un-powdered - bigger size) or when using public toilets. Cotton gloves are good when doing paper work - it prevents cuts.
- Wearing suitable clothing/shoes to avoid getting cuts, grazes, insect bites and stings.
- Not having injections or blood pressure readings in the affected area (lymphoedema wristbands can be bought that raise attention of your condition)
- Treating cuts and scratches immediately with an antiseptic cream so they do not become infected. People with lymphoedema also suggested taking antibacterial wipes with you when you are out.
- Using insect repellents to protect against insect bites
- Moisturising the skin daily to keep it supple (your GP may prescribe a suitable cream). People suggested products included: Manuka Honey moisturiser, Aloe Vera cream, Dermal 500 gel, and using roll-on deodorants. Remember, it is important to find a product that is right for you.
- Avoiding very hot baths and showers, the heat from saunas, steam rooms and sun beds as this may increase swelling
- Using sun cream with a high sun protection factor (SPF) to prevent sunburn eg. Factor 50.

¹ Information adapted from NHS Choices

- Cutting your nails with nail clippers and using hand cream regularly
- Seeing a podiatrist or chiropodist for foot and nail care (tell them you have lymphoedema)
- Wearing shoes that fit correctly and provide support at the top of your feet
- Using an electric razor, if you need to shave in the affected area, to reduce the risk of cutting yourself
- Not wearing tight-fitting clothes or jewellery
- Carefully putting on and taking off your compression garments. If they become too tight contact your specialist lymphoedema practitioner and/or GP. Appliances are available that can assist with putting on lower limb compression garments. Your specialist practitioner can advise you on such products.

Additional suggestions from people with lymphoedema include:-

- Duoderm dressing – good for small breaks, blisters and protects infected tender skin
- For genital lymphoedema use Tea Tree oil in the bath as this can help prevent infection
- Take antiseptic/Anthisan cream with you when you go out for cuts/bites
- Offer opposite hand when hand shaking hands (if right arm affected).
- Use a high factor sun protection under compression garment when going into the sun
- When swimming moisturise beforehand and use an old sleeve/stocking as a Barrier
- Natural sponges are useful for washing as they are gentle
- Many creams and emollients are available on prescription from your GP eg. Diprobase.



Tip 4 – Recognise Early Signs of Infection (Cellulitis)

What is cellulitis?

Cellulitis is a sudden, non-contagious infection of the skin, characterised by redness, swelling and heat, accompanied by pain and tenderness. People with lymphoedema are particularly susceptible to cellulitis because the lymphatic system is damaged and frequently does not function adequately to fight infection. The risk is greater in genital lymphoedema as the area is often difficult to keep clean/free from infection.

What causes cellulitis?

The infection may enter via a break in the skin, such as a scratch or insect bite, a burn, through a pre-existing wound or ulcer, or through an area of skin inflammation, e.g. athlete's foot, eczema or dermatitis. However, it may not be possible to identify the cause immediately and an attack may arise without warning.

What are the symptoms of cellulitis?

It is important to recognise the early signs of an infection in the area affected by lymphoedema. Cellulitis can make you become very unwell very quickly. Contact your GP or NHS24 (if it is out of hours) straight away if you notice any of the following signs of infection in the area affected by lymphoedema:

- redness
- warmth (hot to touch)
- rash
- swelling in the affected area may increase (sometimes dramatically)
- pain, discomfort or ache in the affected area
- red streaks/marks that track up or down from the affected area
- heaviness
- tiredness
- tingling

General symptoms experienced, in addition to those listed above, can be:-

- high temperature
- flu like symptoms
- nausea (feeling sick)
- sickness (vomiting)
- upset tummy
- fever
- headache

What should I do if I develop cellulitis?

Contact your GP or NHS24 (if out of hours) **immediately** as you may need antibiotic treatment or, in severe cases, an admission to hospital. Early treatment of cellulitis in areas affected by lymphoedema is very important, not only because you may become very ill, but because lymph drainage routes risk being damaged further in which case, the swelling in your affected area may worsen. As a result of cellulitis you may become more likely to get cellulitis again (recurrent), and in some cases permanent skin changes e.g. thickening may result. Additional complications such as these make the long-term management of lymphoedema more difficult.

The British Lymphology Society has developed a Consensus Document for doctors regarding the symptoms of (a) an acute attack of cellulitis that requires an admission to hospital or (b) how cellulitis can be managed at home. If managed at home bed rest and elevation of the affected limb is essential. Avoid compression garments during the acute attack. However, they should be replaced as soon as the affected area is comfortable enough to tolerate them. Further details on the Consensus Document and treatment of acute cellulitis are available at: <http://www.thebls.com/consensus.php>

NHS24 provide information on the services they provide. The ‘How to use NHS 24 when your GP is closed leaflet’ link via www.NHS24.com/Explained provides information on what to expect when contacting NHS24 during the out of hours period. It may be useful to read this leaflet so that you understand the process involved and why certain questions are asked by the NHS24 team.


“The first time I got cellulitis I thought I had the flu and just went to bed for a few days. This made the situation a lot worse. It is important for people to know that they need to minimise risks of getting cellulitis due to the further damage it causes every time you get it” Comment from postal response

5 things every GP should know about lymphoedema

Lymphoedema is a chronic and permanent swelling which can affect any area of the body, most commonly affecting the limbs. It can impact on a person’s body image, self-esteem and cause not only physical, but emotional distress as well.

The list below is by no means a definitive or finite description of lymphoedema and is to be used as a guide only.


<p>1 CAUSES</p> <ul style="list-style-type: none"> a. Primary – Hereditary, Congenital b. Secondary – Many Cancers and their treatments, Venous disease, Immobility, Injury, Filariasis <p>2 TREATMENT</p> <ul style="list-style-type: none"> a. Skin care – daily inspection, washing and moisturizing of skin b. Exercise and maintenance of mobility c. Compression garments / multi-layer lymphoedema bandage d. Simple / Manual Lymphatic Drainage e. Referral to specialist clinic 	<p>3 COMPLICATIONS</p> <ul style="list-style-type: none"> a. Cellulitis b. Lymphorrhoea c. Skin changes d. Skin folds e. Social/Psychological impact – lowered self-esteem, difficulties at work, finding clothes etc <p>4 RISK FACTORS</p> <ul style="list-style-type: none"> a. Lymph node removal: irradiation increases the risk b. Venepuncture or blood pressure on at risk or oedematous limb c. Wounds d. Infection – cellulitis & fungal infections
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5 MEDICATION

- a. NONE – condition requires self management and specialist support
- b. Diuretics only if patient has cardiac history
- c. Antibiotics as per Consensus Document for Cellulitis www.thebls.com/consensus.php
- d. Pain control – need to identify cause of pain

www.thebls.com info@thebls.com 01452 790178





Photograph reproduced courtesy of Free Digital Photos.net

Tip 5 – Stay Active

Having lymphoedema doesn't mean that physical activity can't be a part of your life. However, there are some types of physical activity that you will need to be more careful about such as weightlifting or contact sports as these make you more likely to get a cut or break in the skin, bruise, knock or injure your affected limb, which could increase swelling.

Activity helps you to feel better in yourself, maintain a healthy weight and reduces your risk of other health problems. It is also a good way to reduce stress and anxiety. However, some types of medication can make you feel tired and this can affect the kinds of activity you attempt. Find a balance by pacing yourself to ensure that you don't overdo things.

Get to know your own body and be aware of your limitations

Activity can improve lymphoedema because it:

- increases the flow of lymph by working your muscles and reducing swelling
- strengthens your muscles
- keeps your joints flexible, maintaining and improving your range of movement
- improves your posture
- promotes independence
- improves body shape and image

Remember to always wear your compression garment when you 'stay active'. Try to include deep breathing in any daily exercise routines to improve your circulation. Do your activity gradually and regularly, as advised by your physiotherapist or your specialist lymphoedema practitioner, so that you build up a regular routine. Exercises for lymphoedema should be gentle and feel comfortable. The right amount of exercise or activity will vary from person to person.

Too much activity/exercise too quickly may increase swelling. If you're doing too much, your skin may become red, sticky and hot. Long periods of exercise and activity can also increase swelling. Regularly examine your affected area for any increase in the swelling, avoid anything that makes it worse. It is important to talk to your specialist lymphoedema practitioner and/or your GP before starting an exercise or physical activity programme. Exercise should make you breathless but if this becomes unreasonably uncomfortable or seems to make the swelling worse, stop doing it and ask your specialist lymphoedema practitioner or GP for advice.

If you get involved in a type of activity you enjoy, the more likely you are to stick with it. Build up the amount of exercise you do gradually over time. Swimming, aqua fit classes, stretching exercises, Tai Chi, Qi Gong and Yoga are all good options. Swimming and aqua fit are particularly helpful if you have problems with your joints as they work the muscles without putting strain on your joints.

For people with arm, leg, or genital area lymphoedema it is important to always wear support or compression garments when exercising.

You can also keep yourself physically active by doing things around the house, or in the garden, although remember to follow the risk advice in **Tip 2** – looking after your skin. Try to carry on using your body as you would normally do.

Walking by yourself, with others, or with a pet is good exercise and also good socially.

Paths for All are a partnership of organisations committed to promoting walking for health and the development of multi-use path networks in Scotland. For more information please go to <http://www.pathsforall.org.uk/pfa/health-walks/find-a-health-walk.html>

Exercises for Arm Swelling

Your physiotherapist or specialist lymphoedema practitioner will be able to advise on how regularly you undertake the following exercises and how many repetitions should be used:-

- Start exercise from the shoulder working down to hand so that drainage is encouraged to clear the way ahead
- Slowly circle your shoulders in one direction, then the other.
- Practice shrugging and then dropping your shoulders slowly to the count of five.
- Watch your posture, and check in a mirror that your shoulders are level.
- Also, with your affected arm supported, try bending and straightening your arm at the elbow. Repeat this exercise as many times as feels comfortable.
- Sit comfortably and support your affected arm at shoulder height on pillows. Make a fist and then stretch your fingers out straight. Repeat this exercise as many times as feels comfortable.

Exercises for Leg Swelling

For leg swelling, try sitting with your affected leg up, making sure it's supported behind the knee. Do the following exercises at regular intervals during the day while you are resting:

- Move your foot at the ankle to pull your toes up and then point them down.
- Bend and straighten your leg at the knee.
- There are many other exercises that might help - your physiotherapist or specialist lymphoedema practitioner can advise you. What's right for you will depend on your level of fitness.

Exercises for Abdominal or Genital Lymphoedema

Pelvic floor and tummy (abdominal) exercises combined with deep breathing exercises can help reduce abdominal or genital swelling. Your specialist lymphoedema practitioner can show you how to do these. These exercises should be undertaken together with Simple Lymphatic Drainage (SLD) and Manual Lymphatic Drainage (MLD).

Women may have compression garments specially made, which can be padded to protect swollen areas. Sports clothing or underwear containing lycra may also help, depending on how much swelling there is.

In men, a scrotal support or specially made compression garments can be used to help to control swelling. Close fitting lycra shorts (cycling shorts or some types of underwear) can also be useful depending on how much swelling there is. Padding can also help to protect swollen areas. Bandaging can sometimes be used if the penis is swollen.

It is important to wear your garments/supports when doing activities.

"You know your body and its limits. Try not to overdo things when staying active"

Pace Yourself Comment from Inverness Event

Exercise following surgery

For those with cancer related lymphoedema it may be that you have undergone surgery for your cancer, or are undergoing chemotherapy and/or radiotherapy. If you have any of these treatments you should be given verbal and written advice on what exercises you should do.

Gentle stretching exercises help to get the normal use of your arm or leg back after surgery or radiotherapy. In particular, they may help reduce the risk of lymphoedema (especially in women with breast cancer after surgery to remove lymph nodes under the arm). Stretching should be done gently and gradually to help the body develop new

pathways to drain lymph fluid without creating more damage. A physiotherapist will usually show you exercises to help with your arm and shoulder, or leg, movement.

Exercise is an important part of recovery after surgery to remove lymph nodes and it's important to carry on with it for as long as advised. It may be helpful to continue with your exercises even after this period as it helps keep your joints and muscles working well.

Suggestions for additional activities provided by people living with lymphoedema

People have a number of different ways to stay active including: Pilates, sitting on an exercise ball to improve posture, using an exercise bicycle, treadmill or mini trampoline, putting pebbles in your pocket to keep your hands moving when walking, aquacise at the local swimming pool, bicycle riding, dancing along to the Wii or Wii Fit (computer game for television), singing – on your own or with others, and Lebed. If you don't fancy going out to exercise try taking the stairs 2 or 3 times.

For the more adventurous, Dragon Boat racing is becoming a popular group activity. Please note however that some groups have restricted membership for people who live with specific medical conditions.

Resting

It's also important to break up long and busy days with times of resting with your limb in a supported position. If your arm is affected, be careful not to carry anything too heavy. If you need to go shopping, use a trolley or, you may wish to do your shopping online and have it delivered to avoid having to carrying heavy bags.



Tip 6 – Deep Breathing

Deep breathing exercises are important for everyone living with lymphoedema as breathing stimulates lymphatic drainage within the body. Your specialist lymphoedema practitioner will be able to help you perfect the technique and number of repetitions. Deep breathing exercise consists of:-

- Sitting upright in a comfortable chair/in the car or lie on your bed with your knees slightly bent. Rest your hands over your tummy in a relaxed position.
- Take deep breaths to relax.
- As you breathe in, direct the air down to your tummy (abdomen), which you will feel rising under your hands.
- Breathe out slowly by 'sighing' the air out. While breathing out, let your abdomen relax in again.
- Do the deep breathing exercises three to five times, or as recommended by your specialist lymphoedema practitioner.
- Have a short rest before getting up as you may feel dizzy as a result of the exercise.

You can practice deep breathing in all sorts of places, at your desk, blowing bubbles for the children, while watching TV or as part of your usual 'staying active' routine such as yoga, swimming, singing, Tai Chi etc

Tip 7 – Lymphatic Drainage

Simple Lymphatic Drainage

Simple Lymphatic Drainage is something you, a member of your family or carer can do. Choose a time and place where you can do Simple Lymphatic Drainage in a relaxed way without interruption or distraction. Before you start and get yourself into a comfortable position don't forget to do your deep breathing exercises.

The massage is done without the use of oils or creams, but by using your hand very gently to move the skin in a particular direction to encourage the flow of lymph from the superficial into the deep lymphatic vessels.

A little fragrance free talcum powder may be helpful if your skin is sticky and your hand doesn't move freely. If your skin is red when you've finished, then the movement you have been doing has been too hard.

Your specialist will be able to advise and train you in SLD. It is a good idea to take your partner or carer along to the training as they may be able to help you with SLD if your movement is affected.

For SLD: Try using a baby hair brush, or a feather (Comment from Inverness Event)

Manual Lymphatic Drainage

Manual Lymphatic Drainage aims to shift or encourage the extra lymph to move away from the swollen area so it can drain normally. Manual Lymphatic Drainage (MLD) also encourages and improves lymph drainage in the healthy lymph vessels, which helps keep fluid away from swollen areas. Breathing techniques (included in Top Tip 5) are an important part of this treatment.

MLD should only be given by a trained and experienced therapist. There are a number of different techniques for MLD including the Vodder, Földi, Leduc or Casley-Smith methods. A therapist should be trained and certified in at least one of these.

MLD is usually combined with compression garments or bandaging to maintain its effects. MLD can be particularly useful in areas where it's difficult to use compression therapy, such as in the head and neck, and genital areas.

Although some NHS clinics are able to offer MLD as part of lymphoedema treatment, many have strict guidelines as to who they are able to treat with MLD. Therefore, some people have (or choose) to pay for this element of their treatment themselves.

A list of NHS specialist lymphoedema practitioners, in your area, is available from <http://www.lymphoedema-scotland.org>.

If you would like to know how to find your closest qualified MLD therapist who provides MLD services privately (chargeable), contact MLDuk (www.mlduk.org.uk/telephone 0844 800 1988).

Alternatively, you can phone the Lymphoedema Support Network help line on 020 7351 4480. The Lymphoedema Support Network also produces a fact sheet about MLD which is free to members.



Tip 8 – Limb Positioning and Movement

Moving your muscles helps to push fluid around the body, so regular gentle movement or activity/exercise helps prevent fluid from collecting.

These tips will help you position your limb correctly.

If you have arm swelling:

- when sitting down, rest your affected arm on a cushion (if preferable) placed on the arm of a chair so it's fully supported
- try not to rest your arm above shoulder height it - it may reduce blood flow to your arm and increase discomfort
- raise your arm slightly on a pillow when you're lying down
- avoid carrying heavy shopping or other loads with your affected arm
- be careful when you use your affected arm for activities that involve a lot of repeated stretching - some people find that too much activity can make the swelling worse, especially if they're not used to it.
- If using a computer try to use a cushioned rest and find a mouse that is comfortable to use.
- Do not keep your arm in a fixed position for too long a time
- Try supporting your affected arm with a pillow in bed
- Rest your hand on your handbag if standing for a long time (sling effect).
- Put your book onto a cushion instead of holding it up.

If you have leg swelling:

- avoid crossing your legs when you're sitting down
- don't sit with your legs down for long periods - either lie with your legs up on a sofa or fully supported on a footstool
- get up and move about at least once an hour if you can
- avoid standing still for long periods of time - if you have to stand, do the following exercises to stimulate the pump action of your muscles:
 - Raise yourself up on to your toes frequently to tense and relax your calf muscles.
 - Shift your weight from one leg to the other, and transfer your weight from heels to toes, as if walking on the spot.
 - Try rocking back on your heels and forward on to your toes a few times.
- Use the force of gravity – sit with your leg elevated when resting so that your foot is higher than your hip. For night time elevation for leg oedema put something between the base of the bed and the mattress (like a folded blanket).

“Water does not run uphill!” Comment from a person with leg lymphoedema

Limb Positioning during Air Travel

During air travel the air pressure in the cabin is less than the normal air pressure on the ground. The decreased pressure inside a plane's cabin may lead to increased swelling in your affected area as tissue pressures alter. You should always use compression on your affected area when travelling by air and move as much as possible during the flight. It is important to discuss air travel with your specialist lymphoedema practitioner or GP who can suggest some in-flight exercises. The Lymphoedema Support Network (LSN) provides a leaflet containing detailed information on air travel.



Tip 9 – Maintaining a Healthy Weight

Try to keep your weight within the normal range for your height. Your dietician or practice nurse can tell you what your ideal weight should be. You can also ask them for nutritional advice and support. Maintaining your weight may be particularly hard if you have difficulties with mobility.

Some pointers to help you maintain a healthy weight include:-

- **Reduce your calorie intake** by cutting down on fat and sugar in your diet. Only eat as much food as you need.
- **Eat a balanced diet** with lots of fruit and vegetables to make sure you get all the nutrients you need to keep your body healthy.
- **Avoid crash diets.** Losing weight slowly is healthier and you're more likely to keep the weight off for good.
- **Be patient with yourself.**
- **Increase your levels activity** - this will help you to burn up calories. Always get advice from your specialist lymphoedema practitioner or GP before you start an exercise or activity programme. As mentioned earlier in this document it is important to check with your GP or specialist lymphoedema practitioner, take care and pace yourself (especially if you haven't exercised for a while).



Photograph reproduced courtesy of Free Digital Photos.net

“Self-discipline is difficult but keep trying”

Comment from Glasgow Event

Healthy Eating

There isn't a special type of diet that helps to prevent or control lymphoedema. However, eating healthily helps to improve your general health and well-being, which is important when coping with lymphoedema. It also helps to keep your weight healthy.

Try to eat:

- **five** portions of fruit and vegetables a day
- **more** chicken and fish, especially oily fish
- **more** high-fibre foods (wholegrain cereals, brown bread)
- **less** red and processed meat
- **less** saturated fats (pastries, samosas, cheese)
- **less** salt

Also

- **drink responsibly.** Don't forget excessive alcohol intake can affect your health. Alcohol is also high in calories and contributes to weight gain.
- **reduce** portion size (use a tea plate instead of a dinner plate for meals)
- **keep well hydrated** by drinking plenty of water.

Further information on healthy eating, including health recipe ideas and healthy meal planner can be found via the following NHS Choices link:-

<http://www.nhs.uk/LiveWell/healthy-eating/Pages/Healthyeating.aspx>



Photograph reproduced courtesy of Free
Digital Photos.net

Tip 10 – Avoid Smoking

Smoking affects the circulation and may affect the condition of skin which is already damaged by lymphoedema. If you're a smoker, reducing how much you smoke or giving up is the healthiest decision you can make. Stopping smoking also reduces your risk of heart and lung disease, bone thinning (osteoporosis) and smoking-related cancers. By stopping smoking you will feel better, look better and save money.

Reducing and stopping smoking is not always easy and you can get more information on stopping smoking from your GP surgery, your specialist lymphoedema practitioner or community pharmacist. National advice can be obtained via <http://www.canstopsmoking.com/>.

Links to Further Information

“We hope that you have found the information contained in this Guide useful. If you would like to find out more, the following web addresses will provide you with further information on lymphoedema, self management and support available.”

Amanda Platt
Project Manager

The Health and Social Care ALLIANCE Scotland (The ALLIANCE):-

<http://www.alliance-scotland.org.uk>

The Macmillan Lymphoedema Project for Scotland:- <http://www.alliance-scotland.org.uk/what-we-do/macmillan-lymphoedema-project-scotland/>

My Condition, My Terms, My Life:- <http://www.myconditionmylife.org/>

Lymphoedema Scotland:- <http://www.lymphoedema.scotland.org>

The Lymphoedema Support Network LSN:-

Lymphoedema Support Network

St. Luke's Crypt

Sydney Street

London

SW3 6NH

Telephone: 020 7351 0990 (Administration)

Email: adminlsn@lymphoedema.freeserve.co.uk

The British Lymphology Society:- <http://www.thebls.com>

Breakthrough Breast Cancer:-

http://www.breakthrough.org.uk/breast_cancer/treatment/lymphoedema.html

Macmillan Cancer Support:-

<http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Symptomssideeffects/Lymphoedema/Lymphoedema.aspx>

NHS Inform:- <http://www.nhsinform.co.uk/search-results.aspx?q=lymphoedema&t=entiresite>

Patient Opinion:- www.patientopinion.org.uk

ALISS:- visit <http://www.aliss.org/>

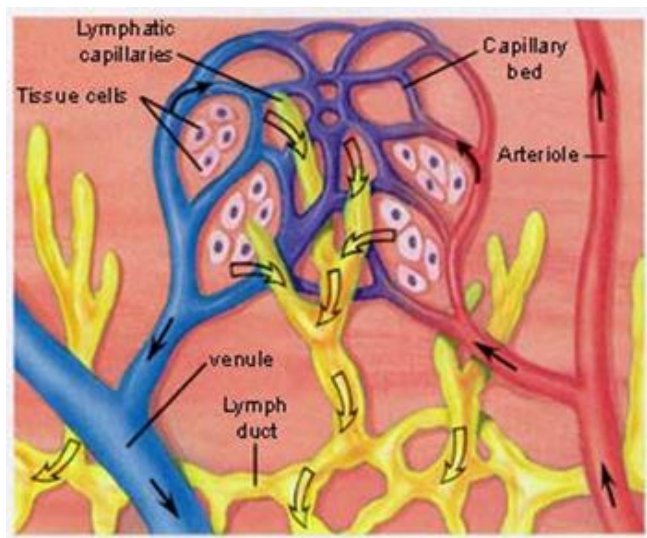
MLD UK:- www.mlduk.org.uk

What is the Lymphatic System? A detailed overview

The lymphatic system is made up of groups of lymph nodes throughout the body, which are connected by a network of lymph vessels.

The lymphatic system:

- acts as a one-way drainage system transporting extra fluid from body tissues into the blood circulation
- contains white blood cells called lymphocytes, which fight infection
- gets rid of waste products produced by cells.



The blood system and lymphatic system make up your body's circulatory system. These systems work together to form part of the immune system, helping to deal with infection. They are also responsible for cleansing the body's tissues and maintaining the balance of fluids in the body.

The lymphatic system contains vessels and channels similar to the blood system. The fluid contained within the lymphatic system is clear in colour and moves in a different way the blood. This clear fluid is called 'lymph'. The name 'lymph' comes from a Latin word for water goddess 'lympha'.

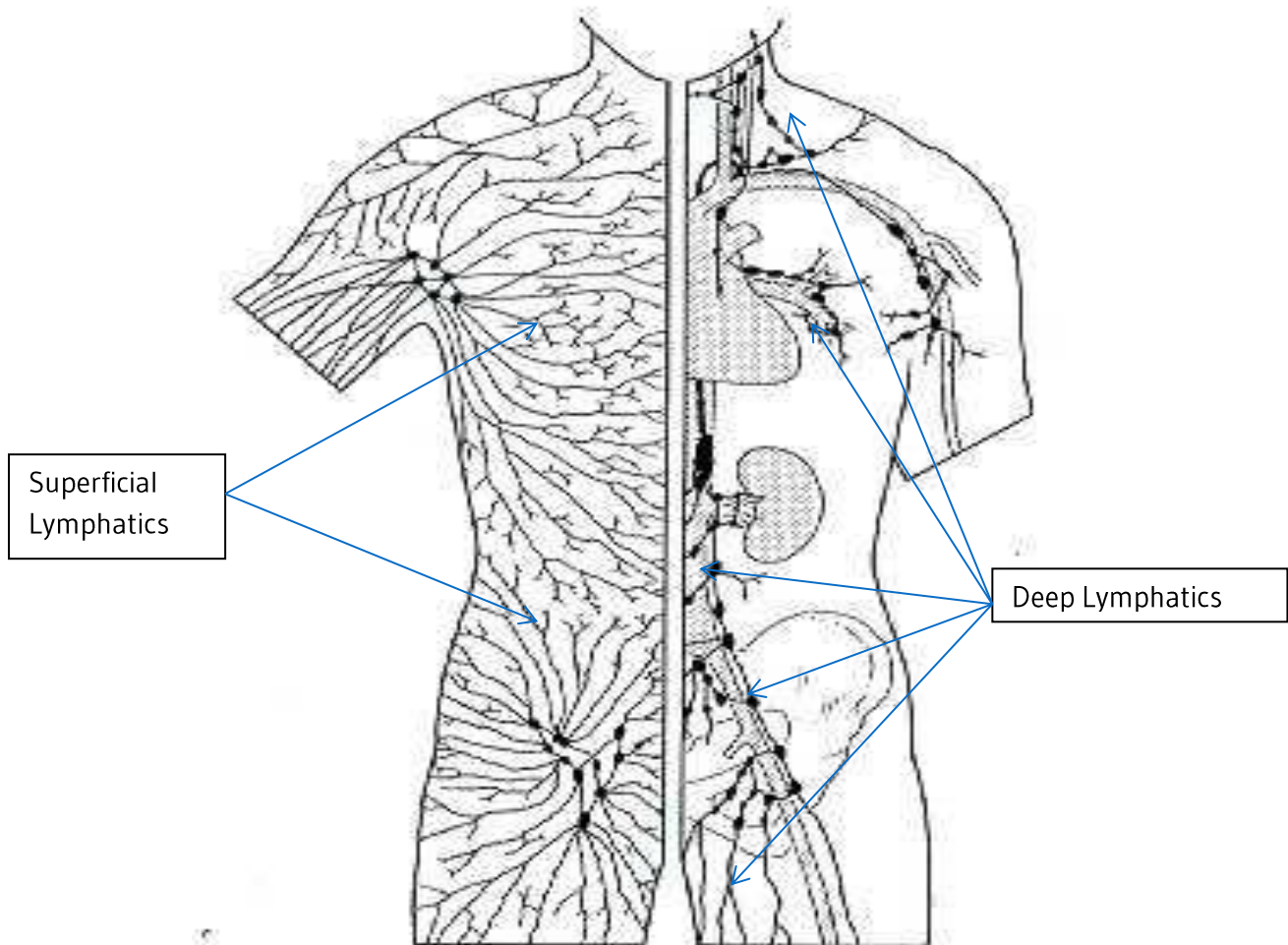
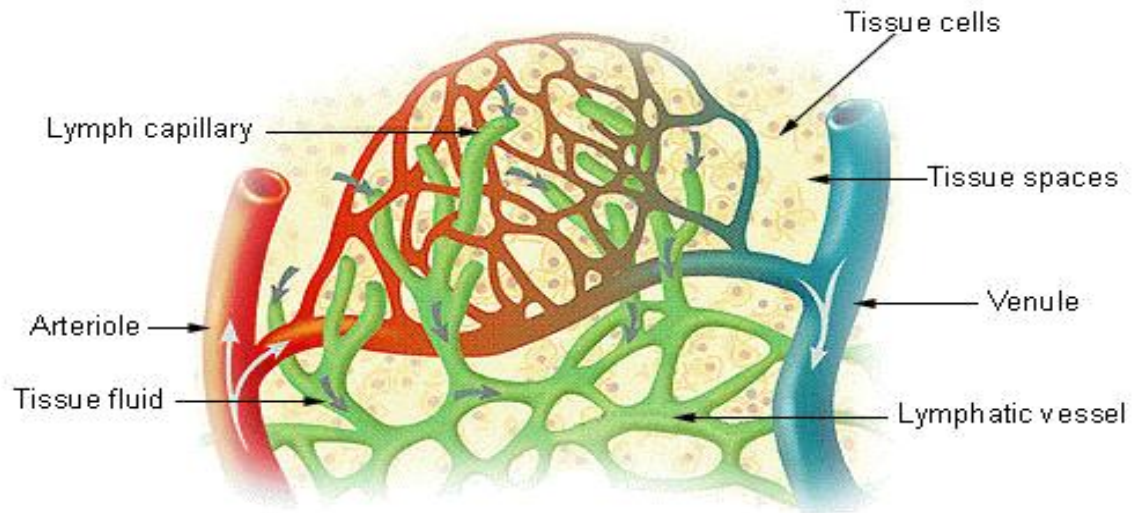


Diagram of superficial and deep lymphatics obtained from the School of Nursing and Health Care, University of Glasgow

The main function of the lymphatic system is to support the immune system and balance fluid within the tissues and cells within your body. Lymphatic capillaries are tiny channels which usually lie just under the skin. They can be easily damaged if the skin is broken. These join onto small lymph vessels which, in turn, join together to form larger lymph vessels. They act as drains to draw away excess protein and water which continually leak from the bloodstream into the spaces between the cells in your body (interstitial spaces). This leaking is normal and happens all the time as part of the way your body works. The draining fluid (lymph) removes large molecules, substances, fragments of damaged cells and foreign matter (bacteria) from the between your cells.

Lymph Capillaries in the Tissue Spaces



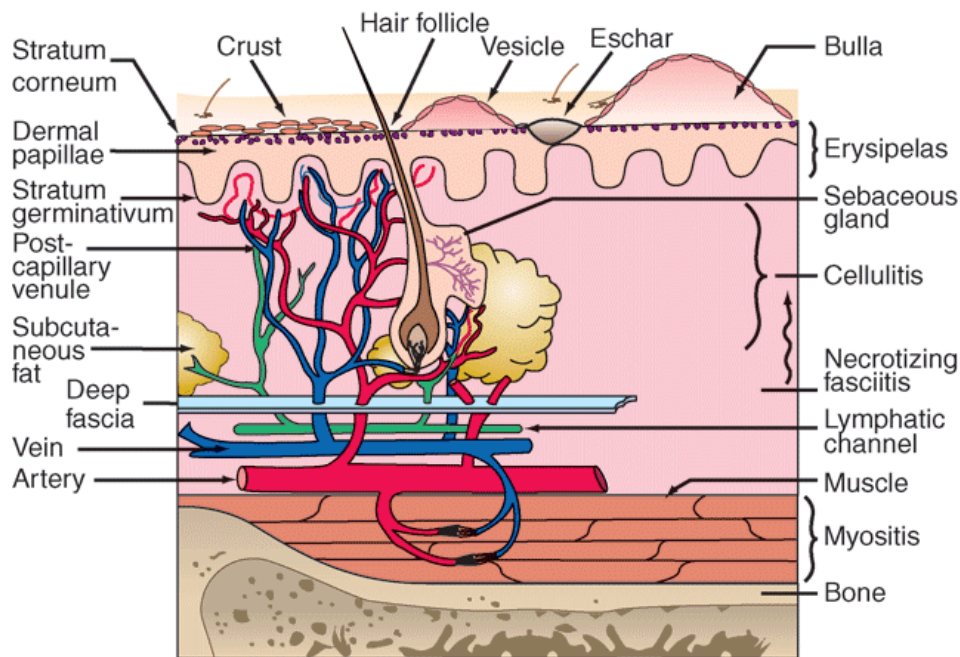
'Lymph Capillaries in the Tissue Spaces' Source: U.S. National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program

Lymph fluid is pulled into the lymph capillaries by a combination of

- a) the movement of nearby muscles
- b) contraction of the walls of the larger lymphatic system
- c) the autonomic nervous system (this controls many organs and muscles within the body but we are usually unaware of its workings because it functions in an involuntary, reflexive way).
- d) the action of breathing.

The continued movement of lymph throughout the body is assisted by many tiny one-way valves inside the lymphatic vessels.

The diagram below shows how close to the skins surface the superficial lymphatic capillaries and vessels (shown in green) are found.



Source: Longo DL, Fauci AS, Kasper DL, Hauser SL, Jameson JL, Loscalzo J: *Harrison's Principles of Internal Medicine*, 18th Edition: www.accessmedicine.com
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On its way along the vessels, lymph is filtered in the lymph nodes (lymph glands).

So, what are Lymph Nodes? Lymph nodes are found throughout the body, but mainly in the neck, armpit, groin and tummy (abdomen). They're made of tissue that contains special cells that help fight infection and disease such as cancer.

Lymph nodes vary in size; some are as small as a pinhead and others are about the size of a baked bean. The number of lymph nodes in the body varies from person to person. Different parts of the body also have different numbers of nodes; in the armpit, for example, there are about 15-30 small nodes.

Lymph nodes contain white blood cells (lymphocytes), which attack and break down bacteria or other harmful cells.

Sometimes the lymph nodes trap bacteria or viruses that they can't destroy immediately. When this happens, the lymph node will usually swell, and become tender and sore to touch. This is usually the sign of an infection which may need treatment with antibiotics.

Sometimes cancer cells spread into the lymph nodes from a cancer in another part of the body. It's also possible for a cancer to start in the lymph nodes themselves (lymphomas). If this happens, the lymph nodes become swollen but are usually painless.

There are different causes for swollen lymph nodes, but if you do develop a painless, swollen lymph node it's important to have it checked by your GP.

Lymph fluid flows through the lymph nodes, which act as a filter by destroying or trapping anything harmful that the body doesn't need. This includes bacteria, viruses, damaged cells or cancer cells. They also start any necessary immune reactions required for healing.

Once filtered by the lymph nodes the lymph fluid then travels through larger lymph channels and drains into the bloodstream. Waste products and the destroyed bacteria are then disposed of with other body waste. The rate at which this happens varies but ranges from between 2-4 litres every 24 hours

The key to the effective working of the lymphatic system is the constant movement of fluid away from the interstitial spaces (the spaces between cells). Lymph flows in one direction only, unlike the blood. Problems can occur when the lymphatic system is unable to cope with the amount of interstitial fluid present, for example when there is too much fluid for the lymphatic channels to drain away. This may occur when the system is damaged following radiotherapy, surgery, following an accident/damage to the lymphatic system, when lymph nodes have been removed or when the lymphatic system hasn't formed properly.

The exact causes of lymphoedema are not always fully understood in all cases. Some people do not develop lymphoedema following surgery or cancer treatment whereas other people do. This may be due to each of us being slightly different. Everyone has a different number of lymph nodes in their body and this makes everyone's lymphatic system individual. It is known that the slight variations that occur from one person to another may play a role in the development of lymphoedema. However the cause of lymphoedema is always a failure of the lymph system to remove fluid, leading to an accumulation of protein rich fluid in the body's tissues which cannot drain away. Accumulation of protein in the tissues causes excess fluid to enter them and, as a result, the tissues swell. This swelling:-

- decreases the oxygenation (the process by which oxygen is transported to the cells in the body by the blood) of the tissues
- interferes with their normal functioning, and makes them heal more slowly than normal.
- 'congests' (blocks) the affected area and the trapped protein causes a 'honeycomb' effect in the tissues, making it more difficult for lymph fluid to pass through.
- Means that the tissues are overloaded with lymph fluid and the shape of the affected area and the skin may begin to change in appearance, texture and shape.