

What is meant by lymphoedema and chronic oedema?

Chronic oedema and lymphoedema are now commonly used interchangeable terms to generally define a permanent swelling which has resulted from either a fault within or damage to the lymphatic system, or a combination of lymphatic, vascular and other causes.



Definitions:

Lymphoedema - "the accumulation of lymph in the interstitial spaces, principally in the subcutaneous fatty tissues, caused by a defect in the lymphatic system. It is marked by an abnormal collection of excess tissue proteins, oedema, chronic inflammation and fibrosis" (Foldi et al 1985)

Chronic oedema - 'a broad term used to describe oedema which has been present for more than 3 months and is not relieved by elevation or bed rest and involves one or more of the following areas: limb (s), hands/feet, upper body (breast/chest, shoulder & back), lower body (buttocks, abdomen), genital (scrotal, penis, vulva), and head, neck and face. Oedema which develops as a result of a failure in the lymphatic system is referred to as lymphoedema but chronic lymphoedema may have a more complex underlying aetiology' (Moffatt et al 2003)



Above picture shows lymphoedema of the leg following successful treatment for lymphoma

The Lymphatic System – physiology of lymphoedema:

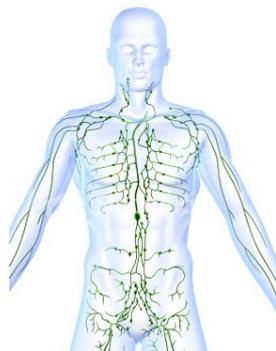
The blood and lymphatic systems make up the body's circulation system. These systems work together to form part of the immune system, helping to deal with infection and are also responsible for cleansing the tissues and maintaining the balance of fluids in the body.

The lymphatic system is part of the body's circulation system and contains vessels and veins similar to the blood system. The fluid contained within the lymphatic system is clear in colour and drains in different pathways than the blood.

The main function of the lymphatic system is to support the immune system and balance fluid within the tissues and cells of the body. Lymphatic vessels drain away excess protein and water which continually leak from the blood into the interstitial spaces (between the cells of the body) This leaking is continuous and the fluid contains large molecules substances, fragments of damaged cells and foreign matter.

Lymph is pumped into and along these vessels by a combination of: the movement of adjacent muscles, contraction of the walls of the large lymphatics, the autonomic nervous system and the action of breathing. This pumping is assisted by many valves inside the vessels.

On its way along the vessels, lymph is filtered in the lymph nodes (lymph glands). Lymph fluid passes through lymph nodes (filtering stations) which are mainly located in the armpits, neck, groins and abdomen. These remove foreign matter (bacteria) and start any necessary immune reactions for healing. Finally the lymph empties into the blood. 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 – 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. This may occur when the system is damaged following radiotherapy or surgery.

The physiological processes of all types of chronic oedema/lymphoedema are not fully understood in all cases. Some people do not develop lymphoedema following cancer treatment. There are additional risk factors and circumstances are individual. For instance, it is known that the anatomy of the lymphatic system varies and this may play a role in the development of the condition following cancer treatment,

There are different types of chronic oedema however pure lymphoedema is caused by a failure of the lymph system to remove fluid, leading to an accumulation of protein rich fluid in the tissues.

Damage to the lymphatic system that compromises its effectiveness or an excess of interstitial fluid which the lymphatic vessels are unable to transport can lead to lymphoedema and chronic oedemas.

The accumulation of protein in the tissues causes excess fluid to enter them and the tissues to swell. The 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. This build up 'congests' the affected area and the protein causes a 'honeycomb' effect in the tissues, making it more difficult for lymph fluid to pass through. 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.

Lymphoedema and risk of infection

Excess protein in the oedematous (swollen) area acts as a stimulus for chronic inflammation (persistent swelling and irritation in the affected area). This results in the formation of excess hardened, or fibrous, tissue. This chronic inflammation causes more blood capillaries to form and to be dilated, making the limb warm and sometimes red in appearance.

This heat, combined with the stagnant protein provides a perfect site for bacterial growth. People with chronic oedema and lymphoedema are given strict advice as to what to do in case of an infection. The immune system in the affected area cannot respond quickly and efficiently to the infection and this can quickly make the person seriously ill. It is imperative that treatment is started immediately. This does not mean the immune system as a whole does not work, just that the area where congested swelling is present. Some people will need to be admitted to hospital for intravenous antibiotics (into a vein).

Fungal infections (e.g. Athlete's Foot) are frequent, and are difficult to treat. Infection places the lymphatic vessels under more stress and can worsen the swelling as it causes further fibrosis (or hardening) of the area making lymph drainage further impaired. The person with lymphoedema is advised to take extra care of their swelling/oedema to avoid infection from mosquito bites, burns, cuts and injury. Some people with lymphoedema suffer with repeated attacks of cellulitis and fungal infections and this must be assessed by a lymphoedema practitioner and appropriate treatment started.

For ease of reading, lymphoedema will be used for the remainder of this information to represent all lymphoedemas and chronic oedema conditions.

Further information regarding symptoms and management of infection can be found in the 'Management of Lymphoedema' section and guidelines for the management of infection in lymphoedema can be found at www.thebls.com/concensus.php

Classification and types of lymphoedema/ chronic oedema

Primary lymphoedema results from abnormalities in the lymph system due to the unusual development of the lymphatic system in utero. Lymphatic vessels may be missing or impaired and therefore unable to function in the usual way.

Primary lymphoedema can be generally divided into three categories related to the approximate age when the condition develops:

- **Congenital lymphoedema:** swelling has been present since birth, commonly in one limb or can involve more than one area of the body
- **Lymphoedema praecox:** the swelling occurs before the age of 35 years, often at the age of puberty generally in the lower body or legs
- **Lymphoedema tarda:** the swelling occurs after the age of 35 years generally in the lower body or legs

Primary, or hereditary lymphoedema, can affect different generations within a biological family and is known to be more common to develop in women than men. Primary lymphoedema generally affects the lower body and legs but in some rarer forms of lymphoedema can affect other parts of the body.

Lymphoedema in children is rare but has many presentations / syndromes and may affect several parts of the body. It is imperative that a thorough medical assessment and investigations are undertaken as to the cause of the swelling. Persistent swelling may be a sign of a more serious underlying problem and therefore a diagnosis of lymphoedema must be fully investigated and any other potential diagnosis eliminated. There are specialist lymphoedema clinics for children in the UK.

Secondary lymphoedema can be caused by cancer treatment when there is damage to a previously healthy lymphatic system. Cancer surgery to remove the tumour and nearby lymph nodes can be a risk factor for developing lymphoedema in the surrounding area nearest to the tumour (For example, in breast cancer lymphoedema can develop in the arm, breast or chest wall of the affected side)

If radiotherapy is given to the remaining lymph nodes which supply the surrounding area (in breast cancer this might be the lymph nodes under the arm) then this may further increase the risk. Radiotherapy can cause further damage to lymph nodes, vessels and the surrounding tissues.

Lymphoedema is most commonly associated with breast cancer however occurs as commonly in people gynaecological (female reproductive system), urological (penile and prostate, cancers), melanoma (a form of skin cancer) and cancers affecting the head, neck and mouth.

If a person has had lymph nodes removed following cancer treatment they should be given the correct information to protect against developing lymphoedema. Many of the clinical nurse specialists/health professionals and doctors will routinely give this information to patients.

Lymphoedema can develop at any point following cancer treatment, and some patients who have not had lymph nodes removed may develop the condition (for example, following surgery and radiotherapy for a bone tumour in the leg). The exact physiological process is still under debate as many factors may be in part responsible. Some people will be more at risk than others for developing the condition but trauma and infection to the 'at risk' area remains the identified overall largest hazard.

In practical terms patients should be given the correct preventative advice to avoid trauma to the 'at risk' area for example, not having blood tests or blood pressure readings taken on the arm following breast cancer treatment.

Further information regarding risk factors and prevention advice for developing lymphoedema is contained in section 4 of this document.

Secondary lymphoedema & chronic oedema can also occur in several other medical conditions such as Rheumatoid Arthritis or Multiple Sclerosis. Trauma such as severe skin infections, cellulitis, can put the lymphatic system under pressure and there is some debate as to whether those who develop swelling as a result of these things may actually have an underlying fault in the lymphatic system, but the condition or additional trauma caused the swelling to start.

Chronic oedemas can develop when there has been damage to the lymphatic and/or vascular system and can occur for many reasons. For instance, people who have trouble walking, problems with veins in their legs or other chronic conditions can develop a degree of chronic oedema. It is now commonly accepted that chronic oedema although may not be strictly 'true' lymphoedema in physiological terms, is a mixed form of the condition and will lead to deterioration of lymphatic function.

In addition, some people **living with advanced cancer or terminal medical conditions** sometimes experience chronic swelling of the legs or large areas of the body. This can be an additional distressing symptom and it may be appropriate for them to be assessed by a lymphoedema specialist who could offer treatment and advice, especially those who may experience leaking lymph fluid (lymphorrhoea) in the swollen area. Treatment can be adapted to suit the individual who may be experiencing other symptoms.

Signs and Symptoms of Lymphoedema & Chronic Oedema

Lymphoedema can occur in any area of the body depending on the cause. If lymphoedema occurs as a result of cancer treatment the 'at risk' area will be where the cancer has been removed or treated and the immediate surrounding area. For example, breast cancer treatment may result in arm, breast or back swelling. Some women after gynaecological cancer treatment notice swelling in the inner upper thigh which may be lymphoedema. More commonly, however, lymphoedema presents as swelling of an arm or leg only and for many the swelling will be minimal.

The following symptoms have been described by patients and may be a sign that lymphoedema is developing:

- Feeling of tightness and heaviness in the limb – noticing that shoes, watch or clothing feels tighter around the limb
- Measurable/noticeable swelling of affected area – slow to develop (never sudden)
- Swelling does not reduce overnight after being in bed or after resting legs on a footstool
- Skin feels tight/bursting/ burning
- Constant or intermittent dull aching or pain in the affected area
- Spontaneous skin blisters and/ or leaking clear fluid from swollen area
- Often the area feels ‘wood-like’
- Skin changes such as thickening of skin, inflammation, fibrosis or in more severe cases hyperkeratosis and papillomas can occur
- Fatigue (extreme tiredness unrelieved by rest & sleep) can accompany lymphoedema
- A tendency towards infection in the form of cellulitis (skin infections) or fungal infection (affecting toe nails or between toes ‘athletes foot’)

Staging of lymphoedema: There are different stages or classifications of lymphoedema depending on how much swelling is present and the condition of the underlying tissues and skin. The majority of lymphoedema is described as ‘mild’ to ‘moderate’ and can be managed without any need for intensive treatment. The table below shows the international grading used for lymphoedema.

Stages of lymphoedema, International Society of Lymphology (Best Practice Framework Document, Lymphoedema Framework Project)

BOX 11 International Society of Lymphology (ISL) lymphoedema staging⁶

ISL stage 0

A subclinical state where swelling is not evident despite impaired lymph transport. This stage may exist for months or years before oedema becomes evident

ISL stage I

This represents early onset of the condition where there is accumulation of tissue fluid that subsides with limb elevation. The oedema may be pitting at this stage

ISL stage II

Limb elevation alone rarely reduces swelling and pitting is manifest

ISL late stage II

There may or may not be pitting as tissue fibrosis is more evident

ISL stage III

The tissue is hard (fibrotic) and pitting is absent. Skin changes such as thickening, hyperpigmentation, increased skin folds, fat deposits and warty overgrowths develop

The extent of the problem: Incidence of lymphoedema

A recent study (Moffatt et al 2003) found that there were 100,000 people in the UK living with lymphoedema and chronic oedema. When compared to the incidence of leg ulcers in the UK which is 75,000 people, the authors have successfully highlighted that lymphoedema is a common and unrecognized problem in the UK.

It should be noted that approximately 20% of people treated for the high risk cancers (listed below) may develop lymphoedema (National Breast and Ovarian Cancer Review 2008) and it is not clear why some people develop lymphoedema rather than others. Following treatment for cancer the incidence of lymphoedema has been varies and some suggested percentages are below:

- Breast cancer: 6 – 49% (Swenson et al 2002)
- Gynecological cancers (vulval, cervical & ovary): 18 – 41% (Sneddon & Lewis 2007)
- Melanoma (skin cancer): up to 41% (Wrightson et al 2003)
- Prostate cancer: up to 66% (more common in those living with cancer – Williams, Franks & Moffatt 2005)
- Bladder cancer: 13 – 20% (Williams, Franks & Moffatt 2005)
- Bone and soft tissue sarcomas: 20 – 30% (Williams, Franks & Moffatt 2005) (NB. This figures represent patients who have undergone radiotherapy high dose treatments)

Sentinel lymph node biopsy and cancer surgery: risk of lymphoedema

In cancer surgery lymph nodes are frequently removed at the time of surgery. The sentinel lymph nodes are the lymph nodes which are nearest or directly drain the fluid nearest to where the cancer tumour has been found. These lymph nodes, instead of all the lymph nodes are removed and tested for cancer cells. If no cancer is found then no further lymph nodes need to be removed. If cancer is found then further surgery may be required to remove more lymph nodes. The technique of testing the sentinel lymph nodes greatly reduced the risk of lymphoedema and other side effects of surgery and is key to identifying cancer spread.

Reassuringly rates of lymphoedema are much lower if only the sentinel lymph nodes are removed as opposed to many or all of the lymph nodes (often referred to as complete/total/axillary or inguinal lymph node dissection)

Continuing research is underway for a better picture of the long term risk of lymphoedema following sentinel lymph node biopsy. The risk appears to be lower following sentinel lymph node biopsy in the axilla (armpit) region than for patients needing the same procedure in the groin (inguinal) lymph nodes. Groin lymph nodes are deeper in the body and when removed surgically require deeper and larger incisions causing more damage to the lymphatics in the region and a larger number of lymph nodes may need to be removed in some cancers.

There are additional factors that may affect the patients' risk for developing lymphoedema. It is known that lymphatic anatomy can vary greatly from person to person and complications such infection following surgery and aftercare affect patient outcome.

Pre operative and preventative advice following surgery regardless of which lymph node removal technique is used should be made widely available for all patients.

Further information regarding the risk and self care for cancer patients is in the Prevention advice section.

Diagnosing Lymphoedema

People who have suspected lymphoedema or chronic oedema will require a thorough assessment. This includes information from the patient regarding the history of swelling; past medical history of any illnesses, accidents, operations and medications; what makes the swelling worse/better together with a physical examination of the affected and surrounding area.

Generally there is no need for any tests to diagnose lymphoedema. The information gained from the in depth assessment and physical examination will be sufficient for an accurate diagnosis in adults.

In some cases however, blood tests may be necessary to identify any other contributing factors, and if the person with swelling has been treated for cancer further scans or details may be required from the patient's cancer specialist.

In rare cases, and where a cause cannot be readily identified, a scan called Lymphoscintigraphy is required. This test is not routine for the majority of people with lymphoedema. It involves the injection of a dye into lymphatic vessels of the affected area (in leg oedema between the toes, in arm oedema the fingers). The scan then traces the lymphatic pathways and the dye moving through the vessels to highlight any abnormality such as missing or incompetent lymphatic vessels or nodes.

FURTHER INFORMATION: LYMPHOEDEMA MANAGEMENT

SKINCARE

Further general advice for all patients with or at risk of lymphoedema is contained in the 'Preventative advice' section

Preventative skincare advice for those at risk of developing lymphoedema following cancer treatment:

- It is recommended that people who have had lymph nodes removed as part of their cancer treatment care for the skin in the 'at risk' area through daily moisturising with a neutral moisturiser such as Aqueous, Diprobase or E45 cream. Moisturising the skin ensures daily inspection of the skin to check for any cuts/insect bites or signs of infection and prevents against dry and cracked skin which may introduce infection For example, if lymph nodes have been removed under the arm following surgery for melanoma (skin cancer) treatment, the patient should use a moisturiser and inspect the skin every day on the arm, chest & back region

- If a skin infection occurs in the limb/area where lymph nodes have been removed antibiotics advised in the 'National Consensus for infection in lymphoedema' should be started. These antibiotics should also be used in patients without any signs of swelling. This is because the lymphatic system may be slow to respond to infection in the usual way as some of the lymph nodes which filter bacteria may be missing or damaged and the drainage system has been disrupted. Symptoms of infection can worsen and make the person very unwell quickly. The correct antibiotics are needed to treat and prevent spread of infection. If the person is unwell with a fever and the infection is severe admission to hospital may be required so that antibiotics can be given intravenously (through a vein). Cellulitis may present in the limb or surrounding area (i.e. following breast cancer surgery infection may occur in the arm, back or chest)

For symptoms of cellulitis see 'Infection' section on next page

SKINCARE: general advice for those with lymphoedema

- Caring for the skin when lymphoedema is present prevents against skin changes and infection. Skin infections (cellulitis) and fungal infections affecting the nails and digits of hands and feet are common



(Below picture shows a fungal infection in the toenails)

- People with lymphoedema are advised to use neutral (neither perfumed, cosmetic nor which contain Lanolin to prevent from an allergic reaction) moisturisers every day on the affected area. Aqueous, Diprobase or E45 creams are useful to prevent dry & cracked skin which may introduce infection

Infection

- **Signs of cellulitis : skin infection**
 - The affected (or neighbouring) area will be red and hot to touch
 - There may or may not be an obvious cause of infection, such as insect bite or a scratch.

- There may or may not be symptoms of fever (temperature) and chills. If the person feels unwell and has a temperature then they **must** see their GP or go to their accident and emergency department immediately. Infection can spread fast and make the person very ill very quickly in those who have a high fever and flu like symptoms.



Picture shows a severe cellulitis (infection) in the leg

Medical attention should be sought at the first signs of infection and antibiotics started immediately. The patient should **rest the affected limb** and observe that the area is not getting any worse or they may need to be admitted to hospital for intravenous antibiotics. If once antibiotics have started and the person continues to feel unwell with a temperature, or if the redness in the affected area is spreading the patient should return to their doctor or accident and emergency urgently. Some people find it helpful to mark the area with a non permanent felt tip pen so they can monitor the red area.

If there is cellulitis (skin infection) present, to prevent the infection from spreading around the body, the person with lymphoedema should NOT:

- Wear their compression sleeve/stocking/garment
- Carry out any exercises or self drainage massage
- Have any intensive lymphoedema treatment (MLD/bandaging/Kinesio taping)
- There has been much research regarding antibiotic therapy for skin infections in lymphoedema so that we generally know what organism has caused the infection, thereby making the treatment easier to ascertain. In lymphoedema certain antibiotics are recommended as they are known to penetrate the congested tissues more effectively than other antibiotic therapy. These guidelines can be found at: www.thebls.com/concensus.php
- It is advised that people with lymphoedema should keep a supply of antibiotics at home and take a course of treatment with them when going on holiday in case of infection
- Some patients suffer with repeated attacks of cellulitis and it is safe and common practice after assessment by a doctor or lymphoedema specialist, for such patients to be given daily low doses of prophylactic antibiotics for 6 months or longer periods. Some patients remain on prophylactic antibiotics for months to years to gain adequate control over repeated bouts of infection

Skin changes due to lymphoedema

- Skin nodules, new skin growths which often have a cauliflower type appearance, known as hyperkeratosis and papillomas can occur. These skin changes are common in the more severe forms of lymphoedema. In severe skin changes, intensive treatments such as bandaging using various materials and dressings are used to soften and improve the skin condition
- The leaking of lymph fluid from the affected area, known as *lymphorrhoea*, can occur. This situation requires an experienced lymphoedema practitioner to assess and plan treatment as soon as possible. Signs of infection need to be carefully observed in this situation as the skin is leaking a new infection can easily penetrate the skin breaks. Nursing care may be needed for sterile dressings & bandages to be applied to the leaking area and changed frequently
- Depending on the cause of the lymphorrhoea multi layered bandages can be applied to the area which mostly halts the leaking in 24 to 48 hours. Bandages can be applied with the usual or a lighter pressure allowing for the patient's physical condition. Follow up care and monitoring of the condition is important as lymphorrhoea may start again and need further treatment. Generally patients may be fitted for compression garments following bandaging treatment for lymphorrhoea to prevent the leaking reoccurring
- Lymph cysts may develop which can also leak lymph fluid, which also requires the expertise of a specialist lymphoedema practitioner to assess and plan treatment best suited to the patient. In some cases surgery to remove the cyst may be appropriate if the cysts are particularly troublesome. This must be carried out by a surgeon with experience in this field and the patient followed up by a lymphoedema specialist

THERAPEUTIC EXERCISE & POSITIONING OF LIMB(S)

Preventative advice following treatment for cancer:

- Gentle exercise and positioning can help to support lymph flow in the at risk area. Following lymph node surgery specific exercises are given to some patients and these should be followed during the post op phase. The exercises demonstrated on the following pages are suitable for use to encourage lymph flow and are useful to accommodate into daily life.
- **NB. If unsure, all patients should check with their doctor before embarking on any exercise regime**

Further information regarding prevention of lymphoedema following cancer treatment can be found in the prevention section.

For people with lymphoedema

- Exercise and deep abdominal breathing increases lymphatic flow. Exercises are prescribed for the person with lymphoedema which stimulate lymph flow by using the joint and muscle pumps i.e. bending/stretching
- People with lymphoedema should be encouraged to use their affected swollen arm or leg normally but take care not to strain the limb.

For example, carrying heavy shopping or strenuous physical activity that may cause strain or injury is **not** recommended, but using the arm to carry out normal light daily activities and exercise is encouraged. Lymph flow relies on movement and the pumping of the muscles & joints

- All patients with lymphoedema should incorporate exercise into their daily routine and build up their regime gradually. Water exercises are particularly helpful as the water can be a buffer against strain/injury
- It is recommended that the compression garments be worn during exercise (not while swimming as this can damage the materials) to support the limb and further encourage lymph drainage
- If swelling is affecting the lower body it is recommended for the patient not to sit or stand for long periods – rest with legs on footstool or in bed/sofa and intermittently move and walk around to encourage lymph drainage
- It is recommended not to over elevate the legs or arms if there is swelling present i.e. raising the end of the bed more than 10 degrees or holding the arms above the head for long periods of time. This may cause the swelling to spread to neighbouring parts of the body and could cause complications in people with high blood pressure or heart conditions
- Support a swollen arm under a pillow when sitting or lying for long periods

COMPRESSION (HOSIERY & MULTI LAYERED LYMPHOEDEMA BANDAGING: MLLB)

Preventative advice following treatment for cancer:

- People who have had lymph nodes removed as part of their cancer treatment do not need to wear compression sleeves or stockings if they do not have any swelling present. If worn this may actually cause swelling to start. This is due to the lymphatic system 'getting used' to compression and then only being able to function properly with compression garments in place
- Some people following cancer treatment are deemed more at risk of developing lymphoedema (see preventative section for more details) and for these people it is sometimes advised they wear a compression garment(s) when going on a long haul flight (for example, over 6 hours). For example, people who have been treated for breast cancer may be able to obtain an armsleeve or a good fitting 'tubigrip'™ to wear during the flight. Those at risk of leg lymphoedema may find 'flight socks' useful to wear. It is important to have the correct size in these items and an advisor in the pharmacy should be able to assist with this and this should be assessed on an individual basis

The use of compression in lymphoedema

- Compression garments are one of the main elements of long term lymphoedema maintenance. Compression garments are available in a range of pressure (known as 'class') and styles to wear anywhere on body (i.e. armsleeves, stockings, underwear garments). A full assessment and physical examination must be carried out before any patient is fitted with compression.



Picture shows a style of full length compression stocking incorporating shorts for comfort

- The compression garments are worn generally only in the day time and removed at night. Stockings are available in a range of colours, styles and fabrics. Armsleeves currently are available in a beige or skin tone colour. The style, thickness of fabric and level of compression will be prescribed according to the patient's clinical condition.
- If the patient has difficulty putting on their armsleeves or stockings there are appliances to help which can be prescribed or purchased to make this easier
- **A prescription charge is applied for compression hosiery, some bandaging items and other aids used in the management of lymphoedema.** Patients are charged per item unless they meet the NHS criteria for free prescriptions www.dh.gov.uk/en/Policyandguidance/Medicinespharmacyandindustry/Prescriptions/NHScosts/DH_4049391 Please note: due to recent change in legislation, patients who have developed lymphoedema as a result of their cancer are now eligible for free hosiery
- Lymphoedema clinics, specialist nurses and GP's can now prescribe a range of these items
- Compression in the form of multi layered lymphoedema bandaging (MLLB) is used during intensive treatment for lymphoedema. The daily application of padding & bandages is used. This is not the same as '4 layer bandaging' used in vascular or leg ulcer dressings. The aim of this treatment can be to encourage lymphatic drainage, reduce the size and volume of the area, improve the skin and reduce fibrosis following cellulitis or to restore the shape of the area. Compression garments can be easily fitted and are more comfortable following the treatment.

When the bandages are in place they provide a working and resting pressure when the limb is moved, and so 'massages' the skin and tissues beneath them



Picture - multi layered bandaging (MLB) of arm

- The bandages are applied daily and kept on for 24 hours before removal and re application so that skincare can be given and the pressure of the bandages maintained. Patients are prescribed exercises to carry out with bandages in place. Treatment with bandaging can last for one to four weeks, or longer, depending on the severity of the patient's condition

MANUAL & SELF (SIMPLE) LYMPHATIC DRAINAGE

Prevention advice following cancer treatment

- People who have had lymph nodes removed as part of their cancer treatment do not need to carry out any self massage or pay for any private manual lymphatic drainage to prevent lymphoedema from occurring. MLD for preventative purposes is not available on the NHS



MLD & SLD for people with lymphoedema

- Manual Lymphatic Drainage (or MLD) is a form of light 'massage'. The techniques used stimulate lymph nodes that drain the affected part of the body and direct lymph flow around the damaged area, whilst encouraging drainage in the congested area. MLD is often used in combination with MLLB (this is sometimes called Complete Decongestive Therapy or CDT explained below). Internationally there are different terminologies used to describe this combination treatment
- MLD is also used where compression can not be easily applied, or as a way to teach the person with lymphoedema how to carry out self drainage. For instance, people with lymphoedema affecting the breast, genital (penis, scrotum or labia) or head & neck areas can have significant improvement with a course of intensive MLD. The person will then need to continue their own self lymphatic drainage on a daily or twice daily basis to achieve long term control of the swelling
- Self lymphatic drainage (SLD) is a simpler form of MLD which can be taught to the patient. The patient (or carer) then carries this out on a daily basis for between 10-20 minutes. This is best combined with deep abdominal breathing. This should only be taught to the patient by an experienced and qualified lymphoedema practitioner and requires a cautious approach in patients with active cancer or other serious medical conditions
- There are different schools of training and MLD techniques and it is worth checking that the practitioner has a recognised qualification. The website MLD UK (www.mlduk.org.uk/) has listings of recommended training and registered therapists for lymphoedema treatment in the UK.

If the lymphoedema is as a result of previous cancer treatment or active cancer it is best to check with the patient's cancer consultant that they are happy for treatment to be given, and that the therapist has good knowledge of the physiology and treatment of cancer

COMPLETE DECONGESTIVE THERAPY (CDT)

- Complete Decongestive Therapy (CDT) is the name given to the combination of MLD, MLLB, exercise and skincare as a treatment. The treatment is carried out on a daily basis for periods of between 1 to 4 weeks. Patients keep the bandages on for 24 hours a day; they are then changed by the lymphoedema practitioner and applied again following skincare & MLD. This can be carried out for periods of weeks and, in severe cases, months
- This treatment, rather than bandaging alone, is particularly effective where there are secondary skin changes or very large misshapen limbs. Often Kinesio taping is applied under the bandaging and over adjoining areas as an additional therapy to encourage the lymphatic flow
- This therapy will need to be continued with the maintenance element of lymphoedema care – wearing of compression garments, self care in the form of skincare, exercises and SLD if appropriate

- Some clinics do not have trained MLD therapists and so multi layered lymphoedema bandaging can be applied and the patient taught their own self lymphatic drainage massage to carry out
- Not all people with lymphoedema require this treatment and all lymphoedema clinics judge patients on their clinical condition as to whether this will improve their swelling.

KINESIO TAPING

- Kinesiology is the scientific study of the anatomy, physiology, and mechanics of body movement and originates from Japan. The taping element is an extension of these theories initially discovered many years ago
- Kinesio taping is the use of a thin type of sticky tape, shown below, which is applied to the skin on and around the affected area in a specific way to follow the lymphatic pathways. It lifts the skin, thereby 'opening' the tiny lymphatic capillaries under the skin helping to increase lymph flow. The tape can be applied and left in place for 5-7 days and placed on any area of the body
- Kinesio tape can be used independently or underneath hosiery or multi layered bandaging. Taping is especially useful for areas of the body where compression can not be easily applied such as on the head & neck, genital and breast regions
- Patients and relatives can be shown how to apply the tape themselves if appropriate
- There needs to be further research in the practice of Kinesio taping for lymphoedema but there are some encouraging results and the practice is now widely available at many lymphoedema clinics. One of the benefits of Kinesio taping is that it is appropriate to use on any area of the body and has no contra indications other than in cellulitis (skin infection). This treatment can be used in any form of lymphoedema or chronic oedema and is helpful in oedema as a result of advanced cancer



LOW LEVEL LASER THERAPY/ULTRA SOUND THERAPY

- The introduction of a hand held low level laser/ultrasound therapy is a relatively new treatment in the UK. The laser/ultrasound works by breaking down fibrosis (hardening/blockage) in the lymphadenomatous tissues, thus promoting lymphatic flow.
- There is further long term research required in the use of low level laser treatment in lymphoedema and this practice is not currently widely available

Why surgery is not a 'treatment' for lymphoedema & chronic oedema

- Historically, many surgical procedures have resulted in lymphoedema patients being left with greater lymphatic damage, deformity and disability. In the past, debulking procedures were used to remove extensive amounts of the swollen tissues and underlying muscles to improve the condition. These procedures are known as 'Charles' or Thompson' techniques. When large proportions of tissue are removed, the remaining healthy lymphatic vessels are also damaged or removed. The surgery does not alter the cause of the lymphoedema and further lymphatic damage occurs as a direct result of the surgery. Swelling frequently returns soon after the procedure and infection and tissue breakdown (wounds) can be a common and long term problem. These procedures are no longer recommended for lymphoedema management
- There are newer procedures in trial phase which use bypass procedures in an attempt to 'reconnect' the lymphatic system. Few patients are eligible for this surgery until further results and long term side effects are known
- **Liposuction** – there are some international clinical trials underway investigating the use of liposuction to treat lymphoedema. It should be noted that currently patients who have not responded to traditional therapies (compression, MLD etc) are eligible to be considered for liposuction. A good reduction of the volume of lymph fluid in the affected area appears to be achieved and patients are still required to wear compression garments intensively (24 hours a day for a few months) and continue with these permanently. Generally these trials have explored the procedures in secondary (cancer related) lymphoedema and patient selection for these procedures are strict. Further research is needed to in this area for the long term benefits or complications

There are 3 situations for lymphoedema where surgical intervention is approved and may be required:

- If lymphangiosarcoma occurs. This is a rare and aggressive cancer which can arise in the lymphadenomatous limb. When diagnosed the only treatment is that of excision (removal of the cancer/affected area through surgery)

- In patients who have had a massive limb reduction through intensive treatment (CDT). To ensure the limb does not 'refill', the skin may need trimming and tightening. This procedure should be carried out by a surgeon with lymphoedema experience and knowledge and the input from a lymphoedema practitioner essential to follow up care of the patient
- In male genital lymphoedema, a scrotal reduction may be necessary and in some cases surgical removal of scrotal lymph cysts is appropriate

Living with lymphoedema: support for patients

Lymphoedema can cause significant disfigurement of the swollen area, changes to the skin and affect everyday living. With appropriate assessment and treatment the condition can be considerably improved and maintained. The condition is not curable and understandably can take some time for the individual to adjust.

In the epidemiology study by Moffatt et al (2003) various effects of living with lymphoedema were highlighted:

- For those with secondary (cancer related) permanent reminder of cancer
- Over 80% of patients had taken time off work due to their lymphoedema
- Overall 95% stated that the oedema affected their employment status with 2% of respondents having to give up work because of it
- Self esteem, body image, relationships – large individual impact
- Despite this, only 3% of patients were receiving formal psychological support
- Chronic pain was experienced by many sufferers: Despite the popular belief that lymphoedema is not painful, 50% of these patients stated that they experienced pain or discomfort in their affected limb with 56% of these taking regular prescribed analgesia.
- Most common pain symptoms were those of aching (36%) heaviness (33%) and tenderness (29%).
- 29% of patients had experienced at least one episode of cellulitis (skin infection) in the affected area over the previous year, with 16 experiencing over 3 infections during this time. 27% of those who experienced infection were admitted to hospital as they required intravenous antibiotics

Practical issues such as finding clothes and shoes to fit, establishing a skin care regime or wearing the compression stockings or armsleeves can take time to adapt. Some lymphoedema clinics have support groups that many patients find useful but these are in short supply.

Alternatively some Primary Care Trusts (PCT's) run courses known as the Expert Patient Programme. These are courses to help anyone with a long term condition. These courses are not generally specific to any one diagnosis but involve patients with a variety of long term conditions. The trained tutor will have a long term, or chronic, condition to guide the group in exploring ways of coping with living with a chronic illness from a practical, social and psychological perspective. Information about these courses can generally be found at GP surgeries or on the following web pages: www.expertpatients.co.uk/public/default.aspx



Macmillan Cancer Support also run 'Living with Cancer' courses supporting people following cancer treatment or those living with cancer experiencing difficulty adapting to normal life or coping with physical or emotional difficulties. Further information can be found at

www.macmillan.org.uk/Get_Support/Ways_we_can_help/Living_with_cancer_courses.aspx

Telephone: 020 7091 2008 or email lwc@macmillan.org.uk

Lymphoedema Clinics

With varying severities of lymphoedema each patient requires an individual assessment. Without treatment the swelling can become very large and cause extensive physical, psychological and social problems for the patient even if the swelling is mild to begin with.

The aim of lymphoedema management is to promote patient independence to self care for their condition. A lymphoedema clinic offers specialist input at diagnosis and a continuing point of contact for any problems associated with the condition and for specialist intensive treatment if required. The majority of patients with lymphoedema will not require intensive treatment regimes.

There are different types of lymphoedema clinics dependant on what the service is able to offer. Some clinics are able to offer all types of treatments while others may need to rely on the input and support of the local community or district nursing teams to help with treatments such as bandaging.

Lymphoedema clinics may be based at a hospital, hospice or GP practice and the national healthcare agenda is promoting the emphasis for provision of such services to be closer to the patient's home. It is expected that many services may be transferred to the local community to best serve the needs of the local population in the next few years.

Health professionals can find details a UK directory of lymphoedema clinics in the UK at the British Lymphology website www.lymphoedema/bls/

The charity for people with lymphoedema, The Lymphoedema Support Network www.lymphoedema.org/lsn/index.html offers a telephone helpline and written advice on the condition, and can advise patients of their nearest clinic. The Lymphoedema Support Network is a dynamic and pro active voice for greater recognition and specialist services for the condition.



When should a patient be referred to a lymphoedema service?

There are many possible causes of oedema and therefore all patients with swelling are not appropriate for referral. If oedema is slow to develop, has occurred after cancer treatment or has been present for more than 3 months and is not relieved by bed rest a referral should be made to a lymphoedema clinic.

The patient should have seen their GP or medical consultant to ensure agreement and funding of the referral to a lymphoedema service.

Some lymphoedema clinics will see cancer patients needing preventative advice for a one off appointment.

Which patients are NOT suitable for referral to a lymphoedema service?

Any patient who has a serious heart, lung, liver or kidney condition who has not been properly investigated for the cause of their swelling. Swelling may occur with these conditions and the underlying cause needs urgent medical attention.

Lymphoedema services **do not** deal with patients who would be more suitable at a leg ulcer, vascular or tissue viability service. For example, people with diabetic leg ulcers with subsequent leg swelling.

ADVICE FOR PATIENTS REGARDING THE PREVENTION OF LYMPHOEDEMA FOLLOWING CANCER TREATMENT

Risk of developing lymphoedema after treatment for cancer -

The risk of developing lymphoedema has many variables and for some it may never occur. Some people are unfortunate to develop lymphoedema soon after surgery to remove lymph nodes or a cancerous tumour and others may develop the condition many years after treatment. It is reported that some people have developed lymphoedema up to 30 years later following cancer treatment which demonstrates the importance of giving patients preventative advice to follow for life following surgery or treatment. It is not easy to identify who may develop lymphoedema but from research and clinical experience of specialist practitioners it is felt that an infection or trauma to the at risk limb/area is often the catalyst

Some people who have been treated for cancers are more at risk than others to develop lymphoedema.

- People with breast cancer who have had breast cancer surgery such as simple mastectomy, lumpectomy, reduced modified mastectomy along with underarm lymph node dissection
- People who have had radiotherapy treatment to the axilla (underarm) or groin region
- People with malignant melanoma of the arms or legs who have had radiotherapy treatment and/or lymph node dissection
- People who have had surgery to head and neck area and lymph node dissection and or radiotherapy

- Men who have had treatment for prostate cancer, testicular cancer and penile cancer who have had surgery or radiotherapy to the pelvic region
- Women who have had treatment for gynaecological or urological cancer, who have had surgery including lymph node removal and/or radiotherapy treatment
- Patients who have had surgery and/or radiotherapy for bone tumours
- Patients with advanced cancer in the breast/chest or pelvic regions
- Other risk factors such as post surgery radiotherapy to the lymph nodes, the persons lymphatic anatomy (this has sometimes been found to be different from one person to another)

In non cancer, hereditary lymphoedema & chronic oedemas the condition may start at different ages and slow to develop but risk factors such as being overweight, difficulty with walking/mobility, skin conditions such as cellulitis and extremes of temperature are all known to exacerbate or start lymphoedema in someone who has an underlying problem with their lymphatic system. If there is a close relative in the family who has lymphoedema it would be beneficial to follow the simple prevention advice listed below and reporting any signs of swelling noticed to the GP and emphasising the family medical history.

There is much research taking place into the occurrence of hereditary and non cancer lymphoedema but still much is unknown. The Lymphoedema Support Network produces in-depth patient information and has a staffed helpline. www.lymphoedema.org/lsn/index.html

General advice for all people at risk of developing lymphoedema and those with the condition:

- **No injections, acupuncture or blood pressure monitoring on the affected or at risk limb (arm/ leg) unless in an emergency. This may mean that some patients who have had lymph nodes removed form under each arm may choose to have blood tests taken from their feet**
- Eat a normal healthy diet and keep weight within normal limits
- Moisturise the skin daily with neutral moisturisers (such as Aqueous/E45 cream or lotion that does not contain Lanolin as this may irritate the skin)
- Protect the skin from cuts, scratches and injury
- Be careful when in the sun – use sunscreen and avoid over exposure
- Use an electric razor in affected area for hair removal (i.e. following lymph node removal in the armpit) - wet shaving, waxing or epilating may cut the skin and introduce infection
- Avoid using a sauna or jacuzzi (extremes of temperature) may precipitate lymphoedema and are best avoided
- Use your arm/leg (s) as normal but avoid activities which are not usual for you to avoid injury or strain
- Gently exercise the arm or leg and avoid sitting in the same position for too long

- **For people who may have a higher risk of developing lymphoedema as described on previous page** - when going on a long haul flight it may be a good idea to have a compression sleeve or stocking fitted to wear for the duration of the flight as some normal swelling may occur and the compression may help to prevent any additional swelling such as lymphoedema developing. Flight socks or 'tubigrip' can be brought in a pharmacy but be careful these are not too small which may cause an elastic band effect, cutting off lymph flow to the at risk area
- If surgery is required to the area in which you have swelling or have had lymph nodes removed, seek advice from your lymphoedema specialist unless an emergency procedure

In addition to the above advice, there are some specific guidelines for people who have been treated for breast cancer or malignant melanoma where lymph nodes have been removed from the axilla (armpit) area:

- No blood pressure measurements on the endangered arm (except in emergency)
- No injections (either in the skin or in the muscles, veins or joints) on the side of the endangered arm (except in an emergency)
- Contact a doctor immediately if signs of infection develop in or adjacent to the arm such as the breast or back
- No acupuncture on the endangered side
- Avoid cold and heat packs directly on the at risk area (extremes of temperature encourage swelling)
- Take care carrying out chores & activities at home such as ironing, cooking & gardening due to risk of injury
- Make sure that bra straps are not too tight and cutting into the shoulder or chest area
- If a breast prosthesis is worn this should be as light as possible to avoid the bra strap cutting into the shoulder or chest
- Avoid tight fitting clothes around the arms, shoulder or chest
- Do not cut your cuticles (risk of infection)
- Take precautions or avoid destinations with high levels of insects (i.e. mosquito bites and risk of infection)
- Avoid frostbite (wear warm gloves during the cold season)
- At the hairdressers, protect your shoulder and upper arm from the heat of the hairdryer

In addition to the general advice, specific advice for patients at risk of developing lymphoedema of the leg following lymph node removal in the groin or for those with lymphoedema:

- Avoid jobs that require standing for several hours
- If at risk of developing lymphoedema observe and seek advice for swelling affecting any part of the legs, including the inner upper thighs
- When sitting for long periods change position regularly
- Maintain good bodily hygiene and dry well between toes
- Do not wear tight shoes and/or high heels that cut off circulation or cause blisters/cuts



- Do not walk barefoot outdoors due to risk of injury and infection
- Do not cut your cuticles
- Avoid injections (either in the skin or muscles or joints) on the endangered side
- Take precautions or avoid destinations with high levels of insects (i.e. mosquitoes)
- Avoid frostbite (wear warm stockings during the cold season)
- Contact your doctor in the event of fungal infections (yellow, broken nails, lacerations between the toes) and treat until infection has resolved
- Contact a doctor immediately in the event of an infection (fever, reddening of the skin, chills)
- Do not wear tight underwear or clothing, take care that belts are not too tight
- Varicose veins should not be treated surgically unless such treatment is absolutely indicated
- If surgery to the at risk area is required monitor closely for signs of infection and seek immediate medical help if infection develops (if your doctor is unaware of the antibiotic guidelines contained in appendix 2 you may want to give them a copy of this)

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