BRITISH LYMPHOLOGY SOCIETY

...actively promoting professional standards

Population needs assessment

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The British Lymphology Society is a multi-disciplinary group of healthcare professionals and other interested parties directly involved in promoting the management of lymphoedema or interested in furthering the work of the Society.

This document is part of a series of British Lymphology Society (BLS) documents which replace and expand the previous BLS guidelines which were as follows:

- Guidelines for the use of Manual Lymphatic Drainage and Simple Lymphatic Drainage
- Chronic Oedema Population and Needs 2001
- Framework for Education 2001 & 2006
- A Strategy for Lymphoedema Care 2001

Current BLS Documents

The current BLS documents are provided to promote professional standards among therapists and those advising or caring for a person with, or at risk of the development of lymphoedema: All documentation has been written in relation to the adult patient with lymphoedema. Data and standards for the treatment of children with lymphoedema have been written by the Children's Lymphoedema Special Interest Group (CLSIG) and can be found on the British Lymphology Society website. www.thebls.com

This document is highlighted below in bold and replaces and adds to the previous document known as 'Chronic Oedema Population and Needs 2001'. The other BLS documents in the current series are as follows:

- An introduction to lymphoedema – overview of the main presentations; pathophysiology of lymphatic disorders; staging of lymphoedema and oedema at the end of life and quality of life findings for those with the condition.
- Evidence review – Management of lymphoedema and recommendations for future research.
- Professional roles in the care of lymphoedema.
- ***Population needs assessment.***
- Standards of practice for lymphoedema services.
- A Lymphoedema Commissioning brief (a version for commissioners and a version for clinical managers 2014).
- Guidance for the management of Obesity Related Lymphoedema (2013; updated January 2016).

1.0 Introduction

1.1 Purpose of this document

- To promote an understanding and recognition of the varying needs of the lymphoedema patient and identify the knowledge and skills required from the lymphoedema professionals to meet those needs.
- Substantial changes have been made to the original BLS document 'Population and needs assessment 2001' to reflect the shift from solely lymphoedema to include chronic oedemas and to encourage the delivery of treatment interventions at the point of care.

1.2 Lymphoedema overview

Lymphoedema arises when the lymphatic system inadequately fulfils its function of regulating fluid balance in tissue spaces. This results in oedema or swelling, which may occur anywhere in the body, but most commonly affects the limbs. It also causes changes in the skin and body tissues, which do not occur in other chronic oedemas. Lymphoedema may be classified as being **Primary** or **Secondary.**

Lymphoedema is not curable, but can be controlled. Key aims of management are to minimise swelling, reduce secondary complications from the swelling, enhance quality of life and promote self-management. The earlier the condition is diagnosed and treatment is initiated, its management is likely to be less costly and treatment outcomes more successful. If untreated, the swelling is likely to worsen over time, cause considerable physical and psychological distress, and impact on activities of daily living and employability. Treatment is likely to be more difficult and costlier overall. It is important that diagnosis is made by a qualified health professional with appropriate training. Individuals with subclinical, established lymphoedema or chronic oedema have the right to comprehensive assessment of their unique needs. Patients should be given information and support, enabling them to become active participants in making informed decisions and setting and achieving realistic goals about treatment and lifestyle choices.

2.0 Defining the needs of those with lymphoedema and chronic oedema

2.1 Defining those 'at risk' of developing lymphoedema (Lymphoedema Framework 2006)

It is important to define the needs of those at risk of, or with physical swelling in order to define the care and needs of those individuals. This section gives an overview of each category, considerations, level of lymphoedema practitioner and knowledge and skills to meet that need.

Stage	Description
Latent (at high risk)	May be primary or secondary. At this stage no swelling is evident despite impaired lymph transport and this stage may exist for months or years before oedema becomes evident. Those with latent lymphoedema are at particular risk of developing clinically evident (established) lymphoedema.
Patients with advanced cancer or at the end of life	Those with advanced cancer or other end of life conditions may be at higher risk of developing oedema or this may develop as part of disease deterioration and other factors. Examples of such factors are: previous cancer treatment (surgery and radiotherapy); active or advanced disease in the abdomen, groin, chest/breast or head and neck regions; active or previous thrombosis; reduced mobility; abnormal liver, renal or thyroid function; reduced function or paralysis of a limb/limbs; cellulitis or recurrent infection; previous trauma/surgery.

Those with the following should be considered at risk of developing lymphoedema:

- Genetic predisposition / family history of chronic swelling.
- Malignancy +/- radiotherapy or surgery in the lymph node area.
- Chronic venous insufficiency.
- Limited mobility or reduced limb function.
- Trauma to lymph nodes/ pathways.
- Chronic skin disorders.
- Recurrent soft tissue infections in the same site such as cellulitis and chronic inflammatory changes.
- Vascular or vein grafting surgery.
- Lymphadenopathy.
- Obesity or morbid obesity.
- Deep Venous Thrombosis (DVT).
- Filariasis.
- Advanced cancer/palliative care.

2.2 Needs of those 'at risk' or with latent lymphoedema

Education, verbal and written information and advice for the individual about:

- Why they are at risk.
- The implications of being at lifelong risk.
- What they can do to minimise the risk of developing lymphoedema including;
    - Normal limb use, isotonic and isometric exercises, breathing exercises and maintaining a healthy weight.

    - Preventing trauma to the skin and general concepts of skin care; avoidance of wearing tight clothing or jewellery.
- What to do if swelling develops.
- What to do if they develop an infection or injury of the skin in the potentially affected area.
- Where to access further information and support from local specialist services or keyworker.
- The contact details for the national patient charity that hold written information for those in an area where services are restricted.

Level of Practitioner appropriate to meet the identified needs:

All healthcare professionals in the Skills Framework should meet these needs if they have the required knowledge and skill detailed below; this may be acquired by a short course of 1-2 days or by work shadowing a lymphoedema specialist practitioner. However, it is particularly important that those health care professionals in a position to promote preventative actions who may be at higher risk of developing lymphoedema, have knowledge to do so.

Knowledge and Skills required to meet the needs:

- Awareness of the nature and development of lymphoedema and predisposing factors.
- Ability to recognise cellulitis and promote agreed national guidelines for the management of acute and recurrent infection.
- Knowledge of and ability to promote lifestyles and activities that minimise the risk of lymphoedema.
- Awareness of local and national resources, referral pathways and processes.

2.3 Defining early lymphoedema (Lymphoedema Framework 2006)

Stage	Description
Early lymphoedema	Swelling has been present for less than 3 months with subtle changes in volume apparent but not including immediate post-operative oedema from surgery. There may be self-reported symptoms of heaviness, aching, clothing or jewellery feeling tighter. There is a subtle volume increase and swelling is relieved by bed rest or elevation. There may be presence of infection (cellulitis) but no secondary skin changes are present. Swelling may be associated with, or occur soon after an acute event such as cellulitis or radiotherapy.

Early lymphoedema may be present in chronic oedema 'at risk' populations where self-care and targeted advice may prevent deterioration in lymphatic function and lifelong lymphoedema, although no body of evidence exists in non-cancer patients. Management of early lymphoedema is through the provision of evidence based care of the skin, movement and positioning of the limb and the wearing of compression garments as deemed appropriate by a qualified health care professional. Occasionally manual lymphatic drainage may be prescribed for those with specific needs. Those who may be affected by early lymphoedema are predominantly those who are undergoing or who have had cancer treatment modalities. Some treatment modalities available to the lymphoedema specialist may be considered to manage some of the skin changes and complications seen as a result of some treatments for cancer. (E.g. the use of Low Level Laser Therapy for the treatment of oral mucositis.) Evidence suggests that when swelling first occurs following cancer treatment, the earlier this is noted and self-care instigated the better the response will be; this early intervention may prevent progression to established lymphoedema.

Swelling should be assessed by a lymphoedema practitioner with training at the appropriate level**.** Where swelling affects an area of the trunk, head and neck or genital regions this should first be assessed by a lymphoedema practitioner at band 6 or above.

2.4 Needs of those with early lymphoedema

Education, verbal and written information and advice for the individual regarding:

- Day to day management of the swollen limb including;
    - Normal limb use, aerobic/resistance exercises, breathing exercises and maintaining a healthy weight.
    - Preventing trauma to the skin, careful skin care and avoidance of wearing tight clothing or jewellery.
    - Daily use of moisturisers and appropriate use of sun cream, insect repellents and creams for treating fungal infections.
    - The wearing of a compression sleeve or stocking – when to wear and take off the garment; what to look for if the garment is ill fitting/worn, who to contact if worn/incorrect fit, and knowledge regarding caring for the garment i.e. washing/drying.
    - Where appropriate, self-lymphatic drainage techniques.
    - What to do if they develop an infection in the skin of the affected area and who to contact.
    - Information regarding symptoms of deterioration or if swelling extends into the adjacent quadrant and who to contact.

Level of Practitioner appropriate to meet the identified needs:

All grades of qualified lymphoedema practitioner as outlined in the skills framework. Healthcare professionals who are "specialists in an adjacent field" (SP) will need additional specified training to assess patients with early lymphoedema especially where garments are required. Where swelling affects an area of the trunk, head and neck or genital region, a lymphoedema practitioner at band 6 or above must first assess the patient i.e. not the specialist in an adjacent field.

Knowledge and Skills required to meet the needs:

Healthcare professionals in an adjacent field will only assess patients with swelling in that specialist field, and not practice outside of their area of expertise. For example, breast care nurses may assess patients with breast cancer related arm swelling, once they have developed the skills and knowledge and undergone relevant training in order to do so, but may not assess patients with other cancer related swelling.

The health care professional will:

- Regularly physically assess patients in their specialist field and be suitably qualified and trained to do so (including receiving regular up-date training).
- Have attended training in assessment of lymphoedema and chronic oedema and be able to determine when a life threatening cause of swelling may be present such as a new or recurrent malignancy, thrombosis or infection and responds to this information appropriately.
- Have awareness of the nature and development of lymphoedema and predisposing factors.
- Have the ability to recognise cellulitis and promote agreed national guidelines for the management of acute and recurrent infection.

- Have knowledge of activities or interventions which relieve or exacerbate the swelling.
- Have attended training in the fitting, selection and re assessment of compression garments.
- If required, be trained in manual lymphatic drainage through an accredited/internationally recognised training school or university.

2.5 Defining uncomplicated (established) lymphoedema (Lymphoedema Framework 2006)

Stage	Description
Uncomplicated (established) lymphoedema	Swelling affecting a limb(s) which has been present for over 3 months and is not relieved by bed rest or elevation. Subcutaneous tissues are soft and normal shape of the limb preserved. Swelling does not affect the head and neck, trunk or genital regions of the body.

People with uncomplicated lymphoedema and chronic oedema do not demonstrate the complications of skin and tissue changes associated with complex lymphoedema, i.e. all of the following apply:

- The swelling is confined to one or two limbs and does not extend to the root of the limb.
- The subcutaneous tissue is predominantly soft and pits on pressure.
- The normal shape of the affected limb is preserved, i.e. Difference in Proximal/Distal ratio (relating to shape distortion in the limb volume measurement) is less than 0.1 in unilateral swelling.
- The skin on the affected limb is healthy and intact.
- There is no arterial insufficiency.
- There is no known malignancy in the truncal quadrant adjacent to the affected limb.
- Renal, cardiac, liver and thyroid problems have been excluded as contributing factors or are well controlled.

In such patients the degree of swelling is likely to be mild, i.e. less than 20% excess limb volume, where this can be determined. However, size is not an effective measure of patient needs and is less important than the above factors.

2.6 Needs of those with uncomplicated (established) lymphoedema

Specific additional needs of those with uncomplicated lymphoedema:

- Regular re-assessment is important until the best possible outcome is achieved and maintained for at least six months.
- Information on where and how to access replacement garments, further information, support following discharge.
- When and how to seek re-referral if discharge criteria met.

In chronic oedema of mixed origin:

- **Lymphatic Compression Bandaging (LCB)** should be applied from tip of toes to above the knees, rather than standard 4-layer compression bandaging (from mid-foot to knees) which may exacerbate the lymphatic damage.
- If the toes are affected it is recommended that the toes are either individually bandaged or the whole foot is bandaged to include the toes. Toe-caps are available on prescription and may be used under the bandages instead of toe bandages.
- Obesity is a common factor in chronic oedema and, as such, a commitment from patients to adhere to advice to reduce body weight and incorporate gentle exercise into their self-care is a core component of management.

***Level of Practitioner appropriate to meet the identified needs*:**

Lymphoedema Practitioner (LP) to assess the individual, interpret the findings, agree a plan of care with the individual appropriate to their needs and make decisions about referral.
Lymphoedema Assistant (LA) to support the LP by undertaking agreed measurements and gathering agreed information as part of the monitoring process, reporting these to the LP in addition to implementing aspects of the care plan as prescribed by the LP, such as providing standard information and replacing garments.
Specialist Practitioners in an adjacent field (SP), if they have undertaken an accredited module in the management of uncomplicated lymphoedema, to assess the individual, interpret the findings, agree a plan of care with the individual and who will seek guidance from an advanced lymphoedema specialist as appropriate - i.e. if the aetiology of the swelling is in doubt; if treatment is unresponsive; where complications occur such as recurrent cellulitis, secondary skin complications or a worsening of symptoms.

Knowledge and Skills required to meet the needs:

All practitioners must have completed an accredited/recognised training module in the management of uncomplicated lymphoedema or, depending upon the career framework, as a keyworker for lymphoedema patients. They will therefore have the skills and knowledge to assess the patients within this group and fully support them in self-care.

2.7 Defining Complex lymphoedema one/multiple limbs (Lymphoedema Framework 2006)

Stage	Description
Complex lymphoedema one limb	Swelling is extensive in one limb. Shape of the limb is significantly distorted with skin folds. I.e. Difference in PD ratio is greater than 0.1 in unilateral swelling. Subcutaneous tissues are firm, thickened and do not pit easily. One or more of the following secondary skin changes are present - fibrosis, hyperkeratosis, papillomatosis, recurrent cellulitis/ fungal infections. Skin is fragile or leaking (lymphorrhoea). The limb is heavy impacting on the individuals' activities of daily life and may have psychosocial consequences.
Complex lymphoedema multiple limbs	Swelling is extensive and affects more than one site of the body. Swelling may affect the limbs, head & neck, trunk, breast, genitals or extend to the root of the limb. Areas affected by lymphoedema have distorted shape and may have skin folds. Subcutaneous tissues are firm, thickened and do not pit easily. One or more of the following secondary skin changes are present - fibrosis, hyperkeratosis, lymphangiectasia, papillomatosis, recurrent cellulitis/ fungal infections. Skin is fragile or leaking (lymphorrhoea). The affected areas are heavy affecting normal function. Activities of daily life and psychosocial health are severely affected by the lymphoedema and symptoms.

Patients with co-morbidities

Those with co-morbidities require medical assessment and/or management prior to management of their lymphoedema and may require treatment plan modifications. Co-morbidities include:

- Evidence of arterial insufficiency, or active malignancy in the truncal quadrant adjacent to the affected limb which may contraindicate compression or modified application
- Venous occlusion or cellulitis, which will delay initiation of compression and lymphatic drainage

- Neuropathy, which impacts on ability to tolerate treatment measures
- Presence of active malignancy, hypoproteinaemia, renal, cardiac or liver failure or thyroid problems. Modifications to treatment may be necessary depending on how well they may be controlled, the prognosis and priorities of the individual and what may realistically be achieved.

2.8 Needs of those with complex (single or multiple limbs involvement)

These groups include people who have developed lymphoedema with any one of a number of complications. Management involves intensive treatment by a specialist and may be modified in some circumstances.

Education, verbal and written information and advice for the individual regarding:

Needs of complicated lymphoedema or chronic oedema

- Provision of more specialised compression garments appropriate to their needs and evaluation of their effectiveness.
- LCB from digits to root of limb when limb is affected.
- Manual Lymphatic Drainage (MLD) – NB although a recommended part of treatment to maximise the effect of treatment, a decision may be made to omit MLD if swelling is clearly confined to limb and does not extend to the root of the limb.

Needs of patients with co-morbidities

- A modified plan of treatment, dependent on the nature and severity of any co-morbidity, the prognosis and the degree of debility. Emphasis is on optimising quality of life, respecting the individual's choices and priorities, and providing psychological support to individuals and their families
- MLD may be contraindicated depending on the nature of the co-morbidity.
- Additional treatment of the oedema may include drug therapy, appliances to aid function and mobility and support to affected limbs by modified compression therapy (garments, wrap systems, support bandaging or Intermittent Pneumatic Compression(IPC)).
- Care may be transferred to an LP when stabilised on a modified management plan, with clear criteria for re-referral.

Level of practitioner to meet the needs:

In general, these presentations require assessment and management instruction by a **Lymphoedema Specialist Practitioner (LSP), Lymphoedema Advanced Practitioner (LAP)** or involvement of a **Lymphoedema Consultant Specialist (LCS).**
Management may be followed up by an LP and LA when the maximum benefit of specialist intensive treatment has been achieved and in periods of stability, with clear criteria for referral back to the specialist. Courses of intensive treatment may be required at intervals to maintain progress.

Knowledge and skills to meet the needs:

- Lymphoedema professionals require specialist skills to address the needs of these groups and should have attended the relevant courses to support their clinical practice.

2.9 Defining Complex, resistant, severe lymphoedema (Lymphoedema Framework 2006)

Stage	Description
Complex, resistant, severe lymphoedema	Complex, resistant, severe lymphoedema which is not responsive to conservative lymphoedema treatment. Swelling volume exceeds 40% (identified in unilateral lymphoedema of the limbs – or in the case of bilateral oedema only if pre-oedema limb volume measurements have been taken) and has serious detrimental effects on physical and psychosocial functioning. This group is rare and requires expert lymphoedema assessment and multi-disciplinary team involvement. Surgery may be indicated to reduce physical and psychological distress. Lymphangiosarcoma may be present and requires immediate assessment and management. The term 'elephantiasis' is commonly associated with this stage of lymphoedema.

2.10 Needs of those with Complex, resistant, severe lymphoedema.

Needs of the patient and their carers vary greatly and cannot be fully described in this document, however, in general, in addition to all the elements of lymphoedema care described elsewhere in this document, these patients require the following:

Education, verbal and written information and advice for the individual regarding:

- Explanation that patients are highly individual and will be complex requiring the input of a specialist multi-disciplinary team experienced in lymphoedema management.
- Patients with complex lymphoedema may require periods of inpatient intensive treatment or surgery may be considered if conservative treatment has been unsuccessful.
- Patients with complex lymphoedema may be at greater risk of life threatening secondary complications such as recurrent cellulitis or Stewart Treves syndrome.

Level of practitioner to meet the needs:

- Complex resistant lymphoedemas represent a rare group of patients with unique and highly specialist needs who require an expert LAP or LCS.
- Diagnostic assessment may demand the use of specialist imaging equipment and multiple specialist medical opinions.

Knowledge and Skills required to meet the needs:

- Good communication needs to be established with all core health care professionals to ensure secondary complications are recognised and reported to the lymphoedema professional as soon as possible.
- Patients with complex resistant lymphoedema should routinely be offered referral to specialist health professionals such as social worker, psychologist and associated allied health professionals.
- Patients will need regular re assessment and teaching in all aspects of self-care to achieve the best outcome for their condition.

2.11 Defining those with lymphoedema due to advanced cancer and oedema at the end of life (Lymphoedema Framework 2006)

Stage	Description
Lymphoedema due to advanced cancer or oedema at the end of life.	Patients with lymphoedema due to advanced disease and who require palliative care can be complex. Lymphoedema can produce distressing and debilitating symptoms. Extensive generalised oedema affecting more than half of the body may be due to multiple factors such as immobility, advanced disease and hypoproteinaemia. Swelling of the limbs can be severe with the involvement of adjacent areas such as the trunk, genitalia and digits. Other symptoms such as severe skin changes, fragile skin and lymphorrhoea, loss of function and independence, in turn, affect lifestyle and function. Patients with advanced disease may not be able to tolerate a full programme of assessment and treatment, but require a palliative approach in which assessment techniques are modified and individual treatments are selected to ease specific symptoms.

2.12 Needs of patients with lymphoedema due to advanced cancer and oedema at the end of life (International Lymphoedema Framework 2010)

A multi-disciplinary approach which encompasses the needs and preferences of the patient is vital for all patients with end of life or advanced cancer related oedema. Oedema in these groups may not have a lymphatic failure or chronic oedema mixed aetiology background, but symptoms may develop rapidly and cause acute distress to the patient. Equally, oedema may signify a symptom which can be relieved and actively managed where disease related treatments have been exhausted.

Lymphoedema practitioners must work alongside all health care professionals, communicating an agreed plan of care and management. Particular individual risks, such as increased risk of cellulitis where lymphorrhoea is present should be emphasised.

Education, verbal and written information and advice for the individual regarding:

Patients with swelling due to advanced cancer or at the end of life and their carers need careful information provision in tandem with associated healthcare professionals regarding:

- The cause and aetiology of the swelling.
- A realistic assessment of what can be done to relieve swelling and associated symptoms.
- Prognosis of the swelling. The development of swelling may be a reflection of the advancement of disease and this needs considered and appropriate communication to the patient.
- Assessment and agreed plans of care should reflect achievable goals reflecting the patient's prognosis and overall health.
- Therapy aims to relieve symptoms, improve quality of life and reduce risks associated with the oedema.
- Regular re assessment is paramount to assess for improvement, deterioration or complications associated with the swelling or interventional treatments.

Patients with oedema in advanced cancer or at the end of life require timely assessment to prevent deterioration, reduce physical and psychological distress and improve quality of life.

Level of practitioner to meet the needs:

- Good skin care, limb positioning and comfort can be applied by all levels of practitioner.
- MLD to be performed by practitioner with training at specialist level.
- LCB to be applied by practitioner with specialist knowledge and training.

Knowledge and Skills required to meet the needs:

- Management of oedema at the end of life or in advanced cancer may consist of one or a combination of lymphoedema treatments and should be delivered by a healthcare professional appropriately trained to do so.
- Healthcare professionals should maintain awareness of actual and potential contraindications and risks to patient safety factoring this into each reassessment of the patient.
- It is imperative to remember that the burden of treatment should not exceed the benefit gained.

Appendix 1:
Summary of Concepts of care for lymphoedema/ chronic oedema

General overview

The overall concepts of care for lymphoedema or chronic oedema are to achieve maximum improvement in terms of reduction in swelling and other symptoms such as pain and discomfort, enhancement of function and skin condition, normalising shape of limb, softening of tissues, minimising occurrence of cellulitis and maximising quality of life, as determined by the individual.

The aim for this group is supported self-care once the condition has been managed and is stable (it must also be recognised that this is not always possible); clear criteria for discharge and re-referral are therefore required. Consideration of the ability of the individual or their carers to apply compression garments is vital before embarking on a course of treatment.

Unless otherwise indicated, all such individuals will require the following:

Comprehensive initial assessment including:

- Full medical and drug history.
- History of swelling and predisposing factors.
- Social, economic and psychological adjustment.
- Consideration of familial/ genetic factors/patterns.
- Support and information needs.
- Personal goals and motivation to self-care.
- Site, extent and degree of swelling.

- Limb volumes, and identification of shape distortion through calculation and comparisons of proximal and distal limb volumes.
- Physiological changes in the skin and tissues.
- Presence and frequency of cellulitis.
- Function and levels of mobility and dexterity.
- The capacity to don and doff compression garments effectively.
- Vascular assessment and status.
- Neurosensory status.

Minimum plan of care appropriate to needs, lifestyle, abilities and self-goals:

- Education, verbal and written information and advice about:
    - The causes of the swelling and risk factors that may exacerbate the swelling.
    - Skin hygiene and moisturising, avoidance of trauma, sunburn, insect bites, venepuncture and observation
    - What to do if cellulitis develops.
    - Normal use of limb, aerobic exercises or graded exercise regimes, breathing exercises.
- Provision of compression garments and / or Velcro wraps if appropriate.
    - Use and care of compression garments and Velcro wraps.
    - Application and removal techniques for compression garments and Velcro wraps
    - Evaluation of garment / Velcro wrap effectiveness
- Weight management advice if necessary
- Teaching of simple lymphatic drainage and evaluation of ability to undertake this (either patient or carer).

- Referral to appropriate specialists where indicated, e.g. in medical specialties, oncology, dermatology, psychology, nutrition, occupational therapy, physiotherapy, lymphoedema, palliative care, podiatry
- What to do and who to contact if condition deteriorates
- Information on where and how to access further information and support.

The full supportive care of the patient through qualified lymphoedema professionals will vary according to the presentation, severity and functional detriment of the lymphoedema.

Appendix 2:
Summary of Oedema Types and Skill requirement from professionals

Stage	Description	Skills and knowledge required to meet the need
'At risk' or latent lymphoedema	Lymphoedema has a wide range of causes and may not become apparent until months or years after the causative event. There may be many factors that predispose an individual to developing lymphoedema or that predict the progression, severity and outcome of the condition. Those with the following should be considered at risk of developing lymphoedema:	'The diverse aetiology of lymphoedema means that patients at risk of lymphoedema will be encountered in a wide variety of primary and secondary/tertiary care settings, e.g. cancer services, vascular surgery units, wound care/ tissue viability services, dermatology services, plastic surgery units and services where patients receive symptom management for advanced cancer.' (Lymphoedema Framework 2006)

	• Genetic predisposition / family history of chronic swelling. • Malignancy +/- radiotherapy or surgery in the lymph node area. • Chronic venous insufficiency. • Limited mobility or reduced limb function. • Trauma to lymph nodes/ pathways. • Chronic skin disorders. • Recurrent soft tissue infections in the same site such as cellulitis and chronic inflammatory changes. • Vascular or vein grafting surgery. • Lymphadenopathy. • Obesity or morbid obesity. • Deep Venous Thrombosis (DVT). • Filariasis. • Advanced cancer/Palliative care	'To guarantee that patients at risk are recognised and their risk of lymphoedema is minimised, each setting should ensure that staff are aware of the potential risk factors for lymphoedema, the appropriate actions to take and relevant referral pathways. By identifying patients at risk of lymphoedema and educating them about the condition, it is hoped that condition severity can be limited through early referral and intervention.' (Lymphoedema Framework 2006) 'Effective identification of patients at risk of lymphoedema relies on awareness of the causes of lymphoedema and associated risk factors, implementation of preventive strategies, and self-monitoring. Patients, carers and healthcare professionals should be aware that there may be a considerable delay of several years from a causative event to the appearance of lymphoedema.' (Lymphoedema Framework 2006)

Mild oedema of a limb or limbs	Swelling may be transient. Swelling at this stage affects the limb(s) only and is pitting. Oedema at this stage may reduce with bed rest and elevation. Subcutaneous tissues are soft with no evidence of fibrosis. The skin is intact however there is a risk of cellulitis and/ or lymphorrhoea through accidental trauma. Swelling may be due to thrombosis and should be considered as part of examination	Lymphoedema may at this stage be managed by a healthcare professional whose area of expertise is in a related field such as specialist palliative care or disease specific nursing and allied health professionals who have undertaken training in the assessment and management of uncomplicated lymphoedema. Otherwise all patients should be first assessed by a palliative care medical consultant with special interest in lymphoedema or a lymphoedema practitioner at band 6 or above to agree multi-disciplinary responsibility and areas of care to be delivered. Healthcare professionals should hold physical assessment skills and disease specific knowledge to comprehend the swelling aetiology and rule out actual contra indications to treatment. Training in the selection, fitting and assessment of the use of compression garments together with all aspects of skin care, movement and positioning of affected limbs is required

Moderate oedema of a limb or multiple limbs	Swelling may affect the trunk, genitals, head and neck or limb(s) causing discomfort. Swelling is not relieved by bed rest, elevation or light compression. There is evidence of secondary skin changes such as fibrosis, and hyperkeratosis and papillomatosis. Swelling may have been present prior to exacerbation but is more pronounced with advanced disease or deterioration of condition. Function of the affected limb/region of the body is affected. Lymphorrhoea may be present and there is a high risk of cellulitis and further maceration of the skin	Patients with moderate and severe oedema in these groups require a lymphoedema practitioner at band 6 and above, or palliative care consultants with experience in end of life oedema, must conduct the initial physical and psychosocial assessment incorporating information from the relevant clinical teams. The full clinical assessment will incorporate psychosocial and carer needs, agree a plan of care with the patient and involve regular re assessment of delivered interventions.
Complex, resistant, severe oedema	There is severe obstruction of the lymphatic & / or vascular pathways through advanced cancer rendering limbs heavy and severely impacting function (i.e. massive disease in the axillary lymph nodes which affects the brachial plexus or a fungating tumour) **And/or** There is severe obstruction of the lymphatic pathways of the head and neck affecting swallow, airway or vision requiring medical intervention (pharmacological, surgical, specialist assessment)	

	And/or Pre-existing lymphoedema had worsened considerably. Extensive and widespread swelling of the affected areas causing shape distortion, secondary skin changes such as skin folds, fibrosis and pigmentation changes	
Lymphoedema due to advanced cancer and oedema at the end of life	Patients who have lymphoedema associated with advanced cancer or who have oedema at the end of life can have complex, debilitating symptoms. Extensive generalised oedema affecting more than half of the body which may be due to multiple factors such as immobility, advanced disease and hypoproteinaemia. Swelling of the limbs may be severe with the involvement of adjacent areas such as the trunk, genitalia and digits. Other presenting symptoms include severe skin changes, fragile skin and lymphorrhoea, loss of function and independence. Lifestyle and function can be affected causing extensive psychological and physical distress. Patients with advanced disease may not be able to tolerate a full programme of assessment and treatment. Techniques are modified and selected to ease specific symptoms.	• Basic skin care, limb positioning and comfort can be applied by all levels of practitioner. • More specialist treatments such as MLD and LCB need to be performed by practitioners with training at specialist level.

Definition of Terms

Cellulitis: an infection of the skin and subcutaneous tissues.

Compression garments: are required for life long containment of oedematous limbs:
- Flat knit: knitted as a flat (made to measure) piece and joined with a seam. Material is firmer and thicker than a circular knit garment.
- Circular knit: knitted on a cylinder with no seam. Garments are shaped by varying stitch height and yarn tension.

Filariasis: is a parasitic disease caused by an infection with roundworms of the Filarioidea type. These are spread by blood-feeding black flies and mosquitoes.

Hypoproteinaemia: is a condition where there is an abnormally low level of protein in the blood. There are several causes and all result in oedema once serum protein levels fall below a certain threshold

Lymphadenopathy: enlargement of the lymph nodes.

Lymphatic Compression Bandaging (LCB): a specialist bandaging technique used to encourage lymph movement and reduce fibrosis.

Lymphangiectasia: dilatation of lymph vessels; may appear as blister-like protuberances on the skin.

Lymphatic filariasis: is a parasitic infection transmitted by mosquitoes. In endemic areas, infection usually occurs in childhood. The parasites damage the lymphatic system, eventually causing lymphoedema.

Lymphangiosarcoma: In the most severe cases of lymphoedema, lymphangiosarcoma, a rare form of lymphatic cancer (Stewart-Treves syndrome) can develop It mainly occurs in patients who have been treated for breast cancer with mastectomy and/or radiotherapy but can also be seen in the lower extremities.

Lymphorrhoea: leaking of lymph fluid from the surface of skin

Manual lymphatic drainage (MLD): a specific form of massage to stimulate the lymphatic system.

Papillomatosis: the development of warty growths on the skin consisting of dilated lymphatics and fibrous tissue.

Stewart Treves Syndrome: See Lymphangiosarcoma.

Abbreviations:
BLS: British Lymphology Society.
CLSIG: Children's Lymphoedema Special Lymphoedema Group.
DVT: Deep Vein Thrombosis.
IPC: Intermittent Pneumatic Compression.
LA: Lymphoedema Assistant.
LAP: Lymphoedema Advanced Practitioner.
LCB: Lymphatic Compression Bandaging.

LCS: Lymphoedema Consultant Specialist.
LP: Lymphoedema Practitioner.
LSP: Lymphoedema Specialist Practitioner.
MLD: Manual Lymphatic Drainage.
SLD: Simple Lymphatic Drainage (self-massage)
SP: Specialist Practitioner in an adjacent field.

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