

Lymphoedema Clinical Definitions and Assessment Guide (5S)

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Background

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This document is an updated version of the BLS Clinical Definitions document (2001), combined with a revised version of the 5S Score.

The 5S score was initially devised in 1996 by Caroline Badger and Eunice Jeffs (Badger and Jeffs 1996) serving as an assessment guide for students gauging the severity of lymphoedema and to assist in the decision of whether specialist referral for treatment was required.

The 5S score was originally designed for unilateral lymphoedema but was never formally published, however it was widely circulated through the Macmillan network (Badger and Jeffs 1996, Macmillan Cancer Relief, 1997). The 5S score has continued to be used in many lymphoedema clinics across the UK.

Introduction

Introduction

Lymphoedema is a complex, chronic condition resulting from impaired lymphatic function, which compromises the body's ability to effectively drain interstitial fluid. This document provides an overview of the mechanisms that lead to lymphoedema formation, alongside a practical assessment guide to support accurate diagnosis. It also provides a recommended format for documenting findings in clinical notes to ensure consistency and clarity. In addition, the document defines and classifies primary and secondary lymphoedema, chronic oedema, and lipoedema, helping to distinguish between these.

Understanding Lymphoedema Formation

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Lymphoedema most commonly affects the limbs but can also involve the head, neck, midline, breasts, or genitalia (BLS 2023). It is not merely mechanical fluid retention but a chronic inflammatory disorder early, comprehensive requiring management. The condition initially arises when fluid entering tissues exceeds lymphatic drainage capacity, either due to high microvascular filtration or low lymphatic uptake (Mortimer and Rockson 2014) leading to fluid accumulation (lymph stasis).

Lymphatic dysfunction may result from congenital malformations (primary lymphoedema) or external factors such as surgery, radiotherapy, cellulitis, trauma, venous disease, reduced mobility or obesity (secondary lymphoedema).

When lymphatic flow is disrupted, excess fluid in the interstitial spaces activates the immune system particularly CD4+ T-cells which release cytokines that hinder lymphatic repair and promote

chronic inflammation (Brown et al. 2023). This inflammatory response drives tissue fibrosis and adipose tissue deposition (Bowman and Rockson 2024) further obstructing lymph flow and perpetuating a cycle of swelling, skin thickening, and increased infection risk and may over time involve structural damage to lymphatic vessels (Lee and Kim 2024, Ly et al. 2017).

Lymphoedema Assessment Guide (5S) Purpose and Intended Audience

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Purpose

This resource aims to support a thorough clinical assessment of lymphoedema using a lymphoedema assessment guide (5S).

The BLS are relaunching the 5S score. This updated version of the 5S score transitions from a scoring system to an assessment guide that ensures healthcare professionals consider all the lymphoedema clinical features represented by the 5S, these are, Skin, Subcutaneous tissues, Site, Size, and Shape.

The updated lymphoedema assessment guide (5S) will include bilateral assessment of and midline lymphoedema to assist standardised in definition and classification of severity of lymphoedema based on symptoms. The new guide also distinguishes the skin and subcutaneous clinical features of lipoedema from lymphoedema. Examples of how clinical information can be used to inform diagnosis and treatment plans are given.

Intended Audience

- Clinicians specialising in lymphoedema who have received formal specialist training
- Clinicians working in related specialties (e.g. leg ulcer management) with experience or training in lymphoedema care

This guide is intended as an aidemémoire, not a teaching tool, and should be used only by qualified professionals under appropriate clinical supervision.

Lymphoedema Assessment Guide (5S) Overview

The 5S supports the assessment of all types of lymphoedema, including:

- Unilateral and bilateral presentations
- Midline and complex cases

The guide provides a structured framework for clinicians to identify key clinical features during examination, specifically:

- **Skin:** integrity and changes
- Subcutaneous tissues: pitting, texture, adipose tissue deposition
- Size: volume or severity lymphoedema
- **Site:** lymphoedema distribution
- Shape: distortion e.g.proximal/ distal ratio and visible asymmetry or shape changes

These features support classification of lymphoedema severity, ISL staging, complication status and help differentiate lymphoedema from lipoedema based on skin and subcutaneous signs.

When combined with a thorough patient history, appropriate measurements, pain assessment, psychosocial assessment and necessary investigations, the guide may also assist in identifying the underlying cause of the condition.

Patient-Centred Approach: The 5S promotes an objective assessment of clinical findings that inform a personalised treatment plan developed in active partnership between clinician and patient. Treatment goals should reflect the patient's own priorities, and the assessment process must remain flexible and holistic, not limited to a single clinical encounter.

Complexity: Assessment findings should be interpreted in the context of the patient's overall complexity, which can affect treatment outcomes. Complexity refers to the combination of health and social factors that influence care planning and delivery. Clinics may utilise tools such as frailty scores or performance status to quantify complexity and align treatment strategies accordingly.

Complexity Level	Definition
High	Significant comorbidities or psychosocial barriers that may impede treatment adherence or effectiveness
Moderate	Some relevant comorbidities or social factors, manageable with tailored support
Low	No significant health or social limitations impacting treatment

The Lymphoedema Assessment Guide (5S)

This section examines the 5S in detail, outlining how their clinical features guide the assessment and classification of lymphoedema stage and severity.

1) Skin

- Dry skin: When lymphoedema is present the skin is more prone to being dry.
- Broken skin: May include dry cracked skin or fissures.
- Fragile skin: Can include skin that is stretched or at risk of skin breakdown.
- Taut/ shiny skin: Can appear shiny and taut due to the pressure of the underlying lymphoedema fluid, commonly seen in palliative or heart failure patients. Can occur when the formation of oedema has been relatively rapid.
- Blisters: Fluid under the surface of the skin, commonly seen in elderly immobile patients, and fragile skin
- Lymphorrhoea: Beads of lymph fluid surfacing through the skin, may be a continuous drip from the swollen area or a damp /wet area of skin. Lymphorrhoea should be treated as a wound. Indicating the need for prompt bandaging treatment to mitigate the risk of cellulitis (NWCS 2023, Thomas et al. 2022).
- Lymphangiectasia: also known as lymphangiomata are dilated lymph vessels. May appear as blister-like protuberances on the skin. Can occur on genitals.

- Papillomatosis: Papillomata are dilated lymphatic vessels which become fibrosed and appear as firm bumps on the skin in wellestablished lymphoedema. This skin change is associated with later ISL stages of lymphoedema.
- Ulceration: Any wound that has been present on the leg or foot for two weeks or more. Indicating the need for holistic assessment and if indicated prompt bandaging treatment to mitigate the risk of chronic ulceration or cellulitis (NWCS 2023).
- Inflammation: All inflammatory presentations (except cellulitis) detailed in the lower limb inflammatory pathway (BLS 2024). Including lipodermatosclerosis, varicose eczema, dermatitis and hemosiderin staining.
- Temperature of skin: assess warmth/coolness of the skin, consider contributing factors to temperature changes.
- Cellulitis: An acute spreading bacterial infection that causes inflammation of the skin and subcutaneous tissues characterised by pain, warmth, swelling and erythema, associated with being systemically unwell cellulitis guidance (BLS & LSN 2025).
- Hyperkeratosis: A thickening of the top layer of the skin (epidermis) causing a crust-like or brown/ yellow plaque formation (BLS 2022). It often harbours bacteria which can cause an odour. The

- presence of hyperkeratosis can indicate the need for patient education on skin care.
- Fungal infection: e.g. tinea pedis, commonly occurs in toe web spaces. The presence of fungal infections can indicate the need for patient education on skin care and can increase the risk of cellulitis.
- Intertriginous dermatitis: a type of moisture associated skin damage (MASD) that commonly occurs in skin folds in those with lymphoedema. e.g. under abdominal aprons, under massive localised lymphoedema (MLE) or in between swollen toes. The presence of MASD can indicate the need for patient education on skin care.
- Scar assessment: observe scar and assess impact on lymphoedema management.
- Loose skin and dimples: Can be associated with Lipoedema (BLS 2023a).

2) Subcutaneous tissues

On palpation the tissues may be described as:

Soft pitting: In some cases may indicate an early lymphoedema presentation, if venous cause may resolve with elevation. Axillary vein compression can cause soft pitting arm lymphoedema in post axillary clearance (Turan et al. 2025, Belgrado 2017). Palliative and cardiac causes of lymphoedema may also present as soft pitting.

- Dense pitting: indicates tissue thickening, firm pressure applied for up to 60 seconds is necessary to assess whether dense pitting is present (Sanderson et al 2024).
- Non pitting: Where lymphoedema is present, non pitting indicates that there is a fibrotic change or adipose tissue deposition in the subcutaneous tissue which does not allow tissues to pit.
- Orange peel skin / Peau d'orange: A textural change commonly seen in midline lymphoedema, characterised by dimpled or pitted skin. Although typically benign in this setting, it warrants clinical vigilance, as this can occasionally signal underlying malignancy.
- Congested tissues: the skin often feels tight (can also be described as taut/tight tissues).
- Cording/axillarywebsyndrome:the appearance of cord-like structures below the skin that may be due to inflammation or thrombosis of lymph vessels, consider appropriate management strategies.
- Doughy, dimpling, mattressing, rice like, loose shapeless subcutaneous tissues: these are clinical features palpable in subcutaneous tissues of lipoedema patients (BLS 2023a, Wounds UK 2017).

Subcutaneous tests

Pitting test: A diagnostic technique whereby sustained manual pressure, up to 60 seconds is applied to the skin to evaluate whether pitting occurs, indicating fluid displacement in the interstitial space.



- Kaposi-Stemmer sign: A test taken to determine the presence of lymphoedema. The ability to pinch the skin at the base of the second digit. If the skin/tissue can not be pinched the test is positive and lymphoedema is confirmed.
- Pinch test (Belgrado pinch test): This is an adapted 'Kaposi-Stemmer sign', identifying the presence of oedema in tissue/ skin on other areas of the body. If the skin/tissue can not be pinched the test is positive and lymphoedema is confirmed (Belgrado et al. 2014, Wigg et al. 2023).

3) Site of lymphoedema

These features are associated with an uncomplicated presentation of lymphoedema.

Lymphoedema symptoms are located within the limb e.g. arm or leg and do not extend beyond. If the lymphoedema extends into the dorsum of the hand or foot only, without affecting the digits it is considered uncomplicated.

These features are associated with a complicated presentation.

- Lymphoedema originates in midline structure, e.g. head and neck, breast, trunk/genital.
- Lymphoedema that originates in the limb and extends into the root of the limb (proximal) e.g. shoulder/breast or hip/genitals.
- If lymphoedema starts in a limb and spreads to the fingers or toes.
- If lymphoedema starts in a limb and spreads to the plantar of the foot or the palmar of the hand.

In lipoedema:

- Typically this affects legs, buttocks, hips and sometimes upper limbs.
- Lipoedema never affects hands or feet.

4) Size of the lymphoedema

Methods of Assessment:

- 1) Circumference measurements: taken at foot, ankle, calf, knee, thigh or hand, wrist, forearm, elbow, upper arm, axilla.
- 2) Volume Calculation with 4cm Segmental Circumferential Measurements: A method involving circumference readings taken at 4 cm intervals along the limb to calculate volume. This method can be used to calculate Percentage excess volume (PEV) and absolute limb volumes.
- 3) Volume Calculation with a Perometer: An infrared measuring device that automatically measures limb volume and shape. This method can be used to calculate percentage excess volume (PEV) and absolute limb volumes.
- 4) Tissue dielectric constant (TDC) A low-power electromagnetic signal that can measure the percentage water content (PWC) in the dermis.
- 5) Bioimpedance. A non-invasive technique that uses a low-voltage electrical current to evaluate extracellular fluid levels in tissues.

Percentage Excess Volume

Calculation for PEV (Fig. 1): This formula quantifies the degree of limb swelling by comparing the volume of the affected limb to the unaffected one. It expresses the excess volume as a percentage relative to the unaffected limb.

The difference in the lymphoedema can only be accurately determined as PEV in cases of unilateral presentation when comparison can

Figure 1: Calculation for PEV:

Volume of affected limb – volume of unaffected limb PEV = \times 100

Volume of unaffected limb

be made to the normal limb. For PEV to be accurate in people treated for cancer related lymphoedema, it should ideally be used with preoperative / pre-treatment measurements (Brunelle et al. 2024) to avoid potential inaccuracies with limb volume comparison, however PEV is still a useful method without pre measurements.

Parameters for severity using PEV:

The category of <10% has been added to distinguish between mild and minimal (Damstra and Halk 2017).

Minimal <10% PEV

Mild 10-20% PEV

Moderate >20%-40% PEV

Severe >40% PEV

Absolute Limb Volumes

For bilateral presentations absolute limb volumes can be used to monitor fluctuations in limb volume to determine size. Absolute volume refers to the total measured volume of an individual limb. Absolute limb volumes can be used to track changes over time and allow clinicians to assess treatment effectiveness and monitor patient outcomes. This method is especially valuable in cases of bilateral lymphoedema or amputation, where comparative analysis between limbs is not feasible.

Volume Calculations:

- Calculations for both PEV (Percentage Excess Volume) and absolute limb volumes can be performed using the BLS LimbStat (other calculators are available).
- The BLS limbstat.
- For guidance, refer to the BLS user guide for limbstat.

Tissue Dielectric Constant (TDC) in Lymphoedema Monitoring

A handheld device using a low-power electromagnetic signal can measure the percentage water content (PWC) in the dermis to a depth of approximately 0.5 cm. This reading, known as the Tissue Dielectric Constant (TDC) provides a reliable indicator of tissue hydration and has emerged as a promising method for assessing the presence and severity of lymphoedema (Toro et al. 2024).

TDC is especially useful in anatomical areas that are difficult to measure with conventional volume assessment methods, such as the midline regions (e.g. breast, head and neck, and genital lymphoedema).

Toro et al. (2024) demonstrated highly statistically significant accuracy in detecting breast cancer related lymphoedema by comparing TDC measurements between affected and unaffected limbs.

Measurement Parameters and Interpretation:

- Ratios are calculated by dividing the TDC value of the affected side by that of the unaffected side.
- A ratio > 1.2 is considered indicative of lymphoedema in limbs, whereas for breasts, a ratio > 1.34 is regarded as significant (Riches et al. 2023).
- A PWC value above 45% is also considered suggestive of lymphoedema.

Bioimpedance Spectroscopy (BIS) in Lymphoedema Assessment

Bioimpedance spectroscopy (BIS) is a non-invasive technique that uses a low-voltage electrical current to evaluate extracellular fluid levels in tissues. It estimates fluid volume by measuring electrical resistance, which varies with tissue conductivity. Higher water content lowers impedance, resulting in an elevated L-Dex.

Clinical Considerations:

- The L-Dex ratio is used to compare affected vs unaffected limbs, providing a quantifiable index of lymphatic fluid accumulation.
- BIS detects fluid only, meaning it does not identify adipose or fibrotic tissue changes. This limits its utility in later stage lymphoedema, where tissue composition may be fatty.
- BIS is particularly valuable in early-stage lymphoedema, when swelling is primarily fluid-based and more responsive to electrical impedance measurement.
- It has not been found useful in detecting truncal oedema.

5) Shape distortion and P:D Ratio in Lymphoedema Assessment

Understanding the P:D ratio:

- The Proximal:Distal (P:D) ratio is a method used to identify shape distortion in unilateral lymphoedema.
- It is calculated by comparing the circumference volumes of a proximal section (e.g. thigh/upper arm) with a distal section (e.g. calf/ forearm) on the same limb.
- A P:D ratio ≤ 0.15 is associated with uncomplicated lymphoedema, where no significant distortion is present.
- A P:D ratio > 0.15 suggests complicated lymphoedema, indicating visible or measurable distortion in limb shape (Badger 1997).

Clinical Considerations:

- It's important to emphasise that early shape changes may be subtle or not visibly apparent, especially in mild presentations.
- The P:D ratio can assist in detecting early changes and guiding treatment decisions.
- The P:D ratio is only used in unilateral cases; for bilateral lymphoedema, distortion must be evaluated subjectively.

Features of Shape Distortion:

- Skin folds: presence of skin folds indicates higher severity of lymphoedema.
- Induration or narrowing: often referred to as inverted champagne bottle shaped legs.

- Massive localised lymphoedema (e.g. pendulous swelling at posterior knees, thighs, or abdominal apron).
- Compression-related changes (e.g. severe toe oedema, oversized dorsum of the foot, prominent knees or shoulders due to illfitting hosiery or poor bandaging technique).
- Positional effects, such as distortion from sleeping in a chair or prolonged dependency.

Lipoedema shape assessment

Waist-to-hip ratio (WHR): in order to exclude central obesity as a cause of a high BMI. A WHR value of ≥0.85 cm is suggestive of obesity in women (World Health Organisation (WHO) 2011) therefore a value of <0.75 may suggest disproportionate fat deposition below the waist which supports a diagnosis of lipoedema (BLS 2023a). For example if a patient had a BMI of 35 and their hip-to-waist ratio was <0.75 the BMI ratio may not be a true reflection of obesity level and this should be considered when setting treatment goals.

A template of the Lymphoedema Assessment Guide (5S) can be found in appendix 1 (page 28). **Clinical Definitions**

Clinical Definitions

Primary Lymphoedema:

is caused due to an intrinsic fault of the lymphatic system and is often, but not always genetic. It is often present from birth, however, the swelling may not develop until later in life.

Genetic disturbances cause many issues with the lymphatics ranging from the structure, drainage pathways, function, or absence of parts of the lymphatic system.

Currently thirty two genes or loci have been linked to Primary Lymphoedema and another 22 are suggested, including Hepatocyte and Growth Factor (HGF), (Alpaslan et al. 2024). Although the condition can be diagnosed by phenotype (the presentation of the lymphoedema), information on the Genotype (the type of gene/ DNA) through genetic testing will assist diagnosis, in addition or combination to lymphatic imaging (Bonetti et al. 2022).

Primary lymphoedema is categorised into 5 subgroups by St George's classification algorithm of lymphatic anomalies (Gordon et al. 2021).

- 1. Lymphoedema associated with other genetic syndromes, such as Noonan or Turner syndrome (where lymphoedema is not the overriding feature of the syndrome).
- Lymphoedema with systemic, or internal, lymphatic problems. For example, pleural effusions, pericardial effusions,

- ascites, chylous reflux, protein losing enteropathy/intestinal lymphangiectasia or in utero swelling (fetal hydrops).
- 3. Lymphoedema that is congenital, so present at birth or within a few months of life (but no systemic involvement and lymphoedema is the predominant problem).
- 4. **Lymphoedema that occurs later in life**, after 1 year of age (but no systemic involvement and the lymphoedema is the predominant problem).
- 5. Lymphoedema that may be associated with lymphatic and vascular malformations, or segmental overgrowth problems.

Secondary Lymphoedema:

arises when a normally functioning lymphatic system becomes impaired due to damage, injury, or physiological overload. The risk increases when multiple factors coexist, compounding the burden on lymphatic function (Damstra and Halk 2017).

This impairment can result from:

- Low lymphatic uptake, due to lymphatic vessel damage or dysfunction, for example, following surgery, radiotherapy, trauma, or cellulitis.
- High microvascular filtration/ output that overwhelms the system, for example, in venous disease or heart failure.

In some cases, contributing factors such as obesity and reduced physical activity may indirectly compromise lymphatic drainage by increasing filtration load and reducing lymph propulsion through muscle movement.

Chronic Oedema: The term chronic oedema may be used interchangeably with secondary lymphoedema. Any tissue swelling that persists longer than three months, no matter the cause, leads on to a failure of the lymphatic system (Mortimer and Levick 2004).

Clinical Sign or Disease

Chronic oedema is considered a clinical sign, while lymphoedema is a disease. Both share the same pathophysiology and can be managed in the same way (Mortimer, 2021).

Classification of Severity with International Society of Lymphology (ISL) staging (ISL 2023)

ISL staging (ISL 2023) is an internationally recognised staging system that can be used by UK clinicians to categorise the severity of their patients lymphoedema. The ISL stage can be determined by patient examination, the 5S assessment guide can inform this.

Classification using the ISL stages 0-III

ISL stage 0: A latent or subclinical condition where swelling is not yet evident despite impaired lymph transport, subtle alteration in tissue

Clinical Definitions

fluid/composition, and changes in subjective symptoms. It can be transitory and may exist month or year before overt oedema occurs.

ISL stage I: Represents an early accumulation of fluid relatively high in protein content. (e.g., in comparison with "venous oedema" which subsides with limb elevation). Pitting may occur. An increase in various types of proliferating cells may also be seen.

ISL stage II involves the permanent accumulation of pathologic solids such as fat and proteins and limb elevation alone rarely reduces tissue swelling, and pitting is manifest.

ISL late stage II The limb may not pit as excess subcutaneous fat and fibrosis develop.

ISL stage III encompasses lymphostatic elephantiasis where pitting can be absent and trophic skin changes such as acanthosis, alterations in skin character and thickness, further deposition of fat and fibrosis, and warty overgrowths have developed. (ISL 2023).

Lipoedema

Lipoedema is a chronic disorder of disproportionate increase in adipose tissue (fat cells) in the legs and sometimes in the arms, almost exclusively affecting women (BLS 2023a). Feet/hands are usually unaffected leading to a 'bracelet' effect at the ankle/wrist. Tissues can be painful on palpation (BLS 2023a).

Clarifying Terminology

Term in the context of this document	Definition
Complicated/uncomplicated	Describes the presentation of lymphoedema, including the location (site) of the lymphoedema or shape distortion.
Complexity	Refers to the patient's broader context, including comorbidities, psychosocial factors, and care challenges.

A patient with low complexity (i.e. no major comorbidities or social factors) may still present with complicated lymphoedema (e.g. genital involvement). Conversely, a patient with high complexity may have an uncomplicated lymphoedema presentation.



Treatment Planning Informed by Lymphoedema Assessment Guide (5S)

Treatment Planning Informed by Lymphoedema Assessment Guide (5S)

All treatment plans should include guidance on weight management, skin care, activity, movement and exercise, along with a tailored compression plan and where appropriate a lymphatic drainage plan.

The lymphoedema assessment guide (5S) focuses on the clinical presentation and achieving the best outcome for the following:

- improving the texture of skin and tissues
- reducing size
- correcting shape distortion
- management of the root of the limb
- maximising lymphatic drainage pathways
- followed by ongoing strategies to maintain any improvements

Additional Considerations when Treatment Planning

- Management of exacerbating factors contributing to lymphoedema formation, including, cellulitis management, cardiovascular factors, obesity and mobility issues. Treatment goals may need adjusting e.g. palliative, heart failure (BLS 2024a) presentations.
- Compression fabric type, including stiffness and knit, affects treatment efficacy must be selected based on skin condition, subcutaneous tissue status, limb contour and patient complexity/ ability to manage self care.

- Graduated compression garments, which when worn on the limb, exert compression on the limb surface which reduces progressively towards the upper leg/arm. For off the shelf compression garments the manufacturers have designed the graduation to be on the profile of a normal shaped limb this should be considered if there is limb distortion.
- Shape distortion caused by poor bandaging technique or positioning (e.g. sleeping in a chair or bandaging that leads to a build up of oedema proximal or distal to the bandage application), when this occurs alternative solutions should be explored in treatment planning.
- Shape distortion may result from the condition itself or from suboptimal interventions such as ill-fitting compression or poor bandaging technique
- Identifying shape distortion is key, it signals a more complex lymphoedema presentation that benefits from DLT.
- Multicomponent lymphoedema bandaging, (formerly referred to as multilayered)(Mosti et al. 2025) or other bandaging techniques are most effective for correcting shape distortion, faster reduction in size and improvement in tissue quality.

- Limbs with significant distortion typically require custom-made compression garments, as standard hosiery may not offer an adequate fit.
- Digit and plantar/palmar lymphoedema requires management.
- Individual assessments may exhibit more than one stage, e.g. right leg stage I, left leg stage II.

Person-Centred Management

Treatment planning must be:

- Collaborative and goal-oriented, involving the patient.
- Based on an individualised approach, recognising that standardised recommendations may need adjustment for unique needs.
- Informed by patient-specific factors such as performance status, frailty, lifestyle, and social factors.

Examples of Lymphoedema Assessment Guide (5S)

Examples of how to use the lymphoedema assessment guide 5S in practice are given below. This is split into 3 sections:

- 1) Relevant medical history, cause/trigger of lymphoedema and contributing factors
- 2) 5S Clinical findings, Skin, Subcutaneous tissues, Site, Size, Shape.
- 3) Final diagnosis including, Primary or Secondary, Cause/s, ISL Stage, Severity, Complicated/Uncomplicated, Complexity.

Section 1: Medical History, Cause and Exacerbating Factors

	Example 1 Upper limb unilateral lymphoedema	Example 2 Head and neck lymphoedema	Example 3 Lower limb (bilateral) and genital lymphoedema	Example 4 Breast (midline) lymphoedema
Relevant medical history Cause/trigger of lymphoedema and contributing factors	60 year old female Left arm lymphoedema secondary to breast cancer and its treatment. Cancer treatment included left mastectomy and axillary node clearance, chemotherapy and chest wall and supra clavicular fossa radiotherapy	60 year old male Submental and submandibular lymphoedema secondary to squamous cell carcinoma of the tongue. Cancer treatment included right neck dissection followed by chemo/radiation	49 year old female Bilateral thigh, genital and lower abdominal lymphoedema secondary to cervical cancer Cancer treatment included surgery (pelvic node dissection), chemotherapy and brachytherapy	64 year old female Right whole breast lymphoedema secondary to breast invasive ductal carcinoma of the breast Cancer treatment included right breast wide local excision and sentinel lymph node biopsy and breast radiotherapy High BMI >40

Section 2: Lymphoedema Assessment Guide: Clinical findings, Skin, Subcutaneous tissues, Site, Size, Shape

5S Clinical Feature	Clinical Findings	Example 1	Example 2	Example 3	Example 4
		Upper limb unilateral lymphoedema	Head and neck lymphoedema	Lower limb bilateral and genital lymphoedema	Breast (midline) lymphoedema
Skin	Dry Broken Fragile Taut/shiny Blisters Lymphangiectasia Papillommatosis Ulceration Lymphorrhoea Inflammation Temperature Cellulitis Hyperkeratosis Fungal infection Intertriginous dermatitis (MASD) in skin folds Scars Lipoedema: Loose skin and dimples	Skin intact Well moisturised Mastectomy scar normotrophic	Skin intact Well moisturised Neck dissection scar normotrophic	Skin intact Well moisturised Papillomatosis to labia (leakage) Peau d'orange changes over mons pubis	Skin intact Taut and shiny skin Dry at the nipple area Skin red over breast

Subcutaneous Tissues Tests: Pitting test Kaposi-Stemmer sign Pinch test	Clinical Findings Soft pitting Dense pitting Non pitting Orange peel skin/ peau d'orange Congested tissues Cording Lipoedema: Doughy, dimpling, mattressing, rice like, loose shapeless sub cut tissues	Example 1 Upper limb unilateral lymphoedema Soft pitting tissues forearm Normal tissues to the upper arm Pinch test positive over forearm	Example 2 Head and neck lymphoedema Dense pitting in sub mental tissues and submandibular tissues (right side). Pinch test positive over site of lymphoedema	Example 3 Lower limb bilateral and genital lymphoedema Dense pitting to both thighs Normal tissues below knees Pinch test positive over site of lymphoedema, including mons pubis	Example 4 Breast (midline) lymphoedema Difficult to test for pitting lymphoedema due to tenderness of skin on palpation Indentations from underwear visible on the skin Tissues appears to have soft pitting lymphoedema
Complicated* or uncomplicated lymphoedema identification * indicates complicated lymphoedema, refer to main document for full details	Limb only Dorsal lymphoedema Digit lymphoedema* Plantar lymphoedema (under foot)* Palmar (of hand) lymphoedema* Root of limb congestion (shoulder/midline)* Originates in midline lymphoedema* Lipoedema: never affects hands or feet	Lymphoedema present from dorsum of hand, no finger swelling Lymphoedema in the forearm No lymphoedema found in the upper arm No lymphoedema to the chest wall	Submental and submandibular (right side) lymphoedema	Lymphoedema present from bilateral knees to hips Lymphoedema present to genitals and lower abdomen	Whole of right breast Axilla lymphoedema No arm lymphoedema

Section 2: Lymphoedema Assessment Guide: Clinical findings, Skin, Subcutaneous tissues, Site, Size, Shape (con't)

5S Clinical Feature	Clinical Findings	Example 1 Upper limb unilateral lymphoedema	Example 2 Head and neck lymphoedema	Example 3 Lower limb bilateral and genital lymphoedema	Example 4 Breast (midline) lymphoedema
Size Methods: Circumference measurements Volume calculations (PEV or Absolute volumes) Tissue Dielectric constant (TDC) and percentage water content (PWC) Bioimpedance	Percentage Excess Volume Minimal <10% PEV Mild 10-20% PEV Moderate >20%-40% PEV Severe >40% PEV Tissue Dielectric Constant Limbs ratio >1.2 Breast a ratio >1.34 A Percentage Water Content > 45% suggestive of lymphoedema	PEV = minimal 7% TDC 1.15	PWC = 85% Right submental region PWC = 60% Left submental region Ratio compared to no lymphoedema region PWC 45% Right 1.88 Left 1.33	Bilateral lymphoedema right leg larger. Absolute volume right 15,645mls Absolute volume left 11,718mls	TDC ratios Quadrant 1: 1.62 Quadrant 2: 1.53 Quadrant 3: 1.8 Quadrant 4: 1.7
Shape Proximal: distal ratio identifies shape distortion in unilateral lymphoedema	P:D ratio >0.15 indicates shape distortion Skin folds induration/narrowing Massive localised lymphoedema Compression related distortion (toe/dorsum/knee) Postural effects/dependency Lipoedema: Waist to hip ratio (WHR)	No shape distortion Based on: PD ratio 0.0	Shape distortion Based on: Face asymmetrical due to presence of lymphoedema in right submandibular tissues (Left submandibular region less impacted)	Shape distortion Based on: Subjective assessment from examination	Shape distortion Based on: Right breast is larger than the left and sits higher up the chest

Section 3: Definition/Diagnosis

Staging of Lymphoedema (International Society of Lymphology) ISL Stage 0-III	Example 1 Upper limb unilateral lymphoedema Stage I Due to soft pitting tissues	Example 2 Head and neck lymphoedema Stage II Due to dense pitting. Positive pinch test over the area with lymphoedema	Example 3 Lower limb bilateral and genital lymphoedema Late stage II Due to dense pitting of thighs, and presence of skin changes (papillomatosis)	Example 4 Breast (midline) lymphoedema Late stage II Due to inflamed skin, dense pitting, peau d'orange, shape distortion
Severity based on PEV or TDC/PWC if used Minimal Mild Moderate Severe	Severity: Minimal Due to: PEV 7%	Severity: moderate Due to: TDC ratio 1.88	Severity: Severe (has been assessed subjectively) The right leg is 34% larger than the left, this cannot be recorded as severity/PEV as there is no normal to compare to	Severity: Severe Due to: TDC 1.8
Complication Status Complicated Uncomplicated	Uncomplicated: Due to no digit or palmar lymphoedema, no lymphoedema in the shoulder/ midline, no shape distortion	Complicated: Due to midline lymphoedema	Complicated: Due to presence of genital lymphoedema and shape distortion	Complicated: Due to originating in midline
Complexity Low Moderate high	Low complexity: Due to ability to self care and no comorbidities	Low complexity: Due to high motivation to self care and no comorbidities	High complexity: Due to difficulties with micturition, infections, sexual activities and unable to work	Moderate complexity: Evidence: high BMI. Is self motivated but in constant pain therefore unable to do self care

Section 3: Definition/Diagnosis

Category	Example 1 Upper limb unilateral lymphoedema	Example 2 Head and neck lymphoedema	Example 3 Lower limb bilateral and genital lymphoedema	Example 4 Breast (midline) lymphoedema
Final Diagnosis Primary/Secondary Causes ISL Stage and or Severity Complicated/ Uncomplicated Complexity	Secondary upper limb lymphoedema: due to breast cancer surgery and radiotherapy ISL stage I Severity: minimal Uncomplicated Complexity: low	Secondary head and neck lymphoedema: due to cancer, surgery and radiotherapy ISL stage II Severity: moderate Complicated Complexity: low	Secondary genital and lower limb lymphoedema: due to cancer, surgery and treatment ISL late stage II Severity: severe Complicated Complexity: high	Secondary breast lymphoedema: due to cancer surgery and treatment ISL late stage II Severity: severe Complicated Complexity: moderate

Lymphoedema Clinical Definitions and Assessment Guide (5S)

Section 1: Medical History, Cause and Exacerbating Factors

	Example 5	Example 6	Example 7	Example 8
	Primary	Multiple cause	Genital lymphoedema (male)	Venous
Relevant medical history Cause/trigger of lymphoedema and contributing factors	64 year old female. Right leg lymphoedema. Onset age 30, no known trigger. Whole right leg lymphoedema, started in foot and progressed to whole leg Recent bowel cancer treatment. Recent increase in frailty	59-year-old female Bilateral lower leg lymphoedema secondary to venous disease and recurrent cellulitis Comorbidities, type 2 diabetes mellitus, essential hypertension, obesity, varicose veins, previous DVT Mental health issues including anxiety impacting self motivation Legs are painful Previous leg ulceration and cellulitis in bandaging treatment Retired last year and mobility reduced	78 year old male Scrotal and penile lymphoedema secondary to carcinoma of the penis Bilateral groin dissection and radiotherapy Reduced mobility, while recuperating	64 year old male Bilateral ankle oedema that has been present longer than 3 months Signs of venous disease Works at a desk

Section 2: Lymphoedema Assessment Guide (5S)

5S Clinical Feature	Clinical Findings	Example 5 Primary	Example 6 Multiple cause	Example 7 Genital lymphoedema (male)	Example 8 Venous
Skin	Dry Broken Fragile Taut/shiny Blisters Lymphangiectasia Papillommatosis Ulceration Lymphorrhoea Inflammation Cellulitis Hyperkeratosis Fungal infection Intertriginous dermatitis (MASD) in skin folds Scars Lipoedema: Loose skin and dimples	Skin intact Taut shiny skin on shin Papilomatosis on toes	Skin intact Fragile skin on lower legs Inflammation (hemosiderin staining) Previous cellulitis Hyperkeratosis	Skin appeared intact, no evidence of skin leakage Skin slightly red at scrotum	Skin intact Hemosiderin staining

5S Clinical Feature	Clinical Findings	Example 5 Primary	Example 6 Multiple cause	Example 7 Genital lymphoedema (male)	Example 8 Venous
Subcutaneous Tissues Tests: Pitting test Kaposi-Stemmer sign Pinch test	Soft pitting Dense pitting Non pitting Orange peel skin/ peau d'orange Congested tissues Cording Lipoedema: Doughy, dimpling, mattressing, rice like, loose shapeless sub cut tissues	Dense pitting to lower leg and dorsum of foot Kaposi-Stemmer sign positive right foot only Pinch test positive over whole leg Thigh mostly non pitting with adipose tissue deposition	Kaposi-Stemmer sign positive bilateral Pinch test over lower legs positive Dense pitting dorsum/ ankle and calf Inflammatory tissue changes /induration lower legs Currently in knee high compression bandaging Congestion of lymphoedema at the knee Bandaging slips back on the foot causing oversized dorsum and toes	Slight indentation on the skin from underwear Soft and pitting tissues Positive pinch test over site of the lymphoedema	Soft pitting tissues at ankles Kaposi-Stemmer sign negative bilateral

5S Clinical Feature	Clinical Findings	Example 5 Primary	Example 6 Multiple cause	Example 7 Genital lymphoedema (male)	Example 8 Venous
Complicated or uncomplicated lymphoedema identification * indicates complicated lymphoedema, refer to main document for full details	Limb only Dorsal lymphoedema Digit lymphoedema Plantar lymphoedema (under foot) Palmar (of hand) lymphoedema Root of limb congestion (shoulder/midline) Originates in midline lymphoedema Lipoedema: never affects hands or feet	Lymphoedema in the whole right leg from toes into the groin, hip and lower buttock Included dorsum and plantar of the foot No genital lymphoedema	Lymphoedema bilateral, in toes, dorsum and plantar of feet Minimal lymphoedema in ankle and gaiter due to use of compression bandage from mid forefoot to below knee Severe upper calf and knee lymphoedema	Scrotal and penile lymphoedema No leg lymphoedema No suprapubic or other truncal lymphoedema	Lymphoedema from ankle to mid gaiter No foot or digit lymphoedema No above knee lymphoedema
Methods: Circumference measurements Volume calculations (PEV or Absolute volumes) Tissue Dielectric constant (TDC) Bioimpedance	Percentage Excess Volume Minimal <10% PEV Mild 10-20% PEV Moderate >20%-40% PEV Severe >40% PEV Tissue Dielectric Constant Limbs ratio >1.2 Breast a ratio >1.34 A Percentage Water Content > 45% suggestive of lymphoedema	PEV 21% Distal PEV 40% Proximal PEV 11%	Foot circumference A Right 30cm Left 31cm Ankle circumference B Right 21cm Left 23cm Calf circumference C Right 30cm Left 31.5 Below knee circumference D Right 50cm Left 52cm	Visible swelling assessed as moderate in terms of size The swelling was not visible when patient fully clothed TDC not used due to patient dignity and also presence of pubic hair TDC could be considered at future consultations to monitor treatment outcomes	Circumference measurements Foot circumference A Right 23cm Left 22.5cm Ankle circumference B Right 22cm Left 22cm Calf circumference C Right 36cm Left 36 Below knee circumference D Right 32.5 left 32.5

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5S Clinical Feature	Clinical Findings	Example 5 Primary	Example 6 Multiple cause	Example 7 Genital lymphoedema (male)	Example 8 Venous
Shape Proximal: distal ratio identifies shape distortion in unilateral lymphoedema	P:D ratio >0.15 indicates shape distortion Skin folds induration/narrowing Massive localised lymphoedema Compression related distortion (toe/ dorsum/knee) Postural effects/ dependency Lipoedema: Waist to hip ratio (WHR)	Shape distortion Based on: P:D ratio 0.4 Skin folds on toes Toe oedema prominent	Shape distortion Based on: distortion in feet, with large forefoot and toe oedema, narrow ankle and congestion in knees Caused by bandage application technique	No shape distortion: Based on: No skin folds No penile distortion on examination	No shape distortion: Based on: Fits into off the shelf size chart Visual inspection

Section 3: Definition/Diagnosis

Category	Example 5 Primary	Example 6 Multiple cause	Example 7 Genital lymphoedema (male)	Example 8 Venous
Staging of Lymphoedema (International Society of Lymphology) ISL Stage 0-III	ISL late stage II Due to tissue changes and advanced skin features	ISL late Stage II Due to tissue changes and distortion (treatment induced)	ISL stage II Due to skin and tissue changes	ISL stage I Due to soft pitting tissues, reduction with elevation
Severity based on PEV if used Minimal Mild Moderate Severe	Severity: moderate Due to PEV 21%	Severity: moderate Based on circumference measurements	Severity: moderate Based on size	Severity: minimal/mild Based on circumference measurements and clinical assessment
Complexity Low Moderate High	Moderate complexity: Due to recent bowel cancer treatment and increased frailty	High complexity: Due to mental health, social factors and complex comorbidities	Moderate complexity: Due to reduced mobility	Low complexity Due to absence of comorbidities, or social factors that will impede self care
Complication Status Complicated Uncomplicated	Complicated: Due to toe and plantar lymphoedema, extension into the buttock, and shape distortion	Complicated: Due to shape distortion and extension of lymphoedema into toes and plantar of foot	Complicated: Due to genital lymphoedema	Uncomplicated: Due to no digit or plantar lymphoedema and no trunk/ genital lymphoedema and no shape distortion
Final Diagnosis Primary/Secondary Causes ISL Stage and or Severity Complicated/ Uncomplicated Complexity	Primary unilateral lower limb lymphoedema: Subgroup 4 ISL late stage 2 Severity: moderate Complicated Moderate complexity	Secondary bilateral lower limb lymphoedema: Due to venous disease, cellulitis, high BMI and reduced mobility ISL late stage 2 Severity: moderate Complicated High complexity	Secondary scrotal and penile lymphoedema: Due to cancer surgery and treatment ISL stage 2 Severity: moderate Complicated Moderate complexity	Secondary lower limb lymphoedema: Due to venous disease ISL stage I Severity: minimal/mild Uncomplicated Low complexity

Notes

Notes

Please make any notes in the space below:

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Appendix 1: Lymphoedema Assessment Guide (5S) Template

Appendix 1: Lymphoedema Assessment Guide (5S) Template

Relevant medical history	
Cause/trigger of lymphoedema and contributing factors	

Lymphoedema Assessment Guide (5S)

The checklist is used to identify significant clinical features that will later inform the diagnosis. Clinicians can also add general comments to the template such as well moisturised skin or comments about nails or distribution of symptoms.

5S clinical feature	Findings Checklist	Details of Findings
Skin	Pindings Checklist Dry Broken Fragile Taut/shiny Blisters Lymphorrhoea Lymphangiectasia Papillommatosis Ulceration Inflammation Temperature Cellulitis Hyperkeratosis Fungal infection Intertriginous dermatitis (MASD) in skin folds Scar assessment	Details of Findings
	Lipoedema: Loose skin and dimples	

5S clinical feature	Findings Checklist	Details of Findings
Subcutaneous Tissues Tests: Pitting test Kaposi-Stemmer sign Pinch test Site Complicated or uncomplicated lymphoedema identification	Soft pitting Dense pitting Non pitting Orange peel skin/peau d'orange Congested tissues Cording/axillary web syndrome Lipoedema: Doughy, dimpling, mattressing, rice like, loose shapeless sub cut tissues Limb only Dorsal lymphoedema Digit lymphoedema*	
* indicates complicated lymphoedema, refer to main document for full details	Plantar lymphoedema (under foot)* Palmar (of hand) lymphoedema* Root of limb congestion (shoulder/midline)* Originates in midline lymphoedema* Lipoedema: never affects hands or feet	
Size Methods: Circumference measurements Volume calculations (PEV or Absolute volumes) Tissue Dielectric constant (TDC) Bioimpedence	Percentage Excess Volume Minimal <10% PEV Mild 10-20% PEV Moderate >20%-40% PEV Severe >40% PEV Tissue Dielectric Constant Limbs ratio >1.2 Breast a ratio >1.34 Percentage Water Content > 45% suggestive of lymphoedema	

Appendix 1: Lymphoedema Assessment Guide (5S)

Lymphoedema Assessment Guide (5S) (con't)

5S clinical feature	Findings Checklist	Details of Findings
Shape	P:D ratio >0.15 indicates shape distortion	
Proximal: distal ratio identifies shape	Skin folds	
distortion in unilateral	Induration/narrowing	
lymphoedema	Massive localised lymphoedema	
	Compression related distortion (toe/dorsum/knee)	
	Postural effects/dependency	
	Lipoedema: Waist to hip ratio (WHR)	

Clarifying Terminology

Term in the context of this document	Definition
Complicated/Uncomplicated	Describes the presentation of lymphoedema, including the location (site) of the lymphoedema or shape distortion.
Complexity	Refers to the patient's broader context, including comorbidities, psychosocial factors, and care challenges.

Definition/Diagnosis

Category	Classification
Staging of Lymphoedema (International Society of Lymphology)	
ISL stage 0	
ISL stage I	
ISL stage II	
ISL late stage II	
ISL stage III	
Severity based on PEV if used Minimal Mild Moderate Severe	
Complication Status Complicated Uncomplicated	
Complexity Low Moderate High	
Final Diagnosis Primary/Secondary Causes Severity/ ISL stage Complicated/Uncomplicated Complexity	

