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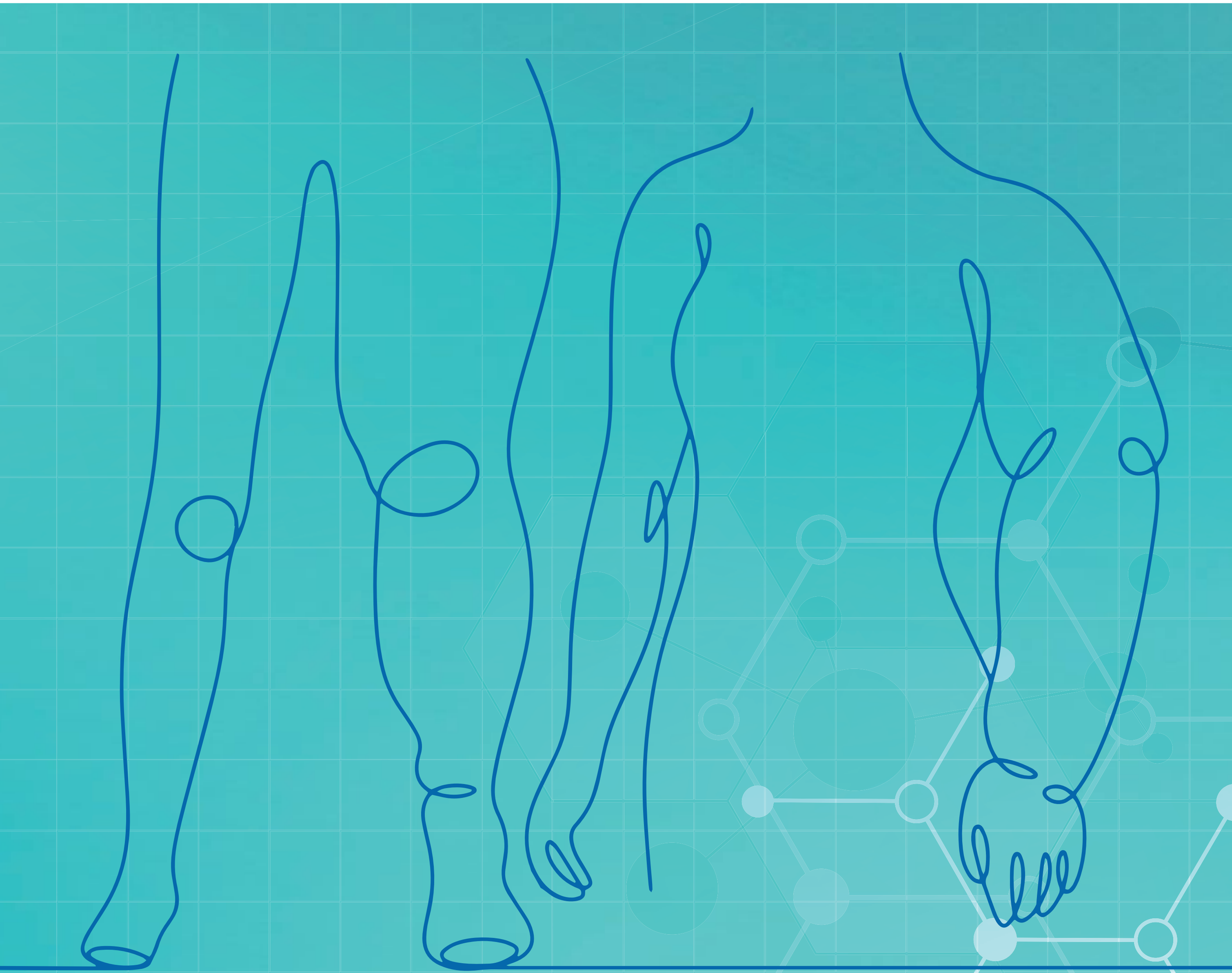

Lymphoedema management in primary care

What every healthcare professional should know

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Executive summary

Lymphoedema can severely affect daily activities and quality of life. It occurs when the lymphatic drainage system fails to work effectively. Lymphoedema affects all ages. There are estimated to be almost 450 000 people living with lymphoedema in the UK. It is more common than the combined number of people with multiple sclerosis, motor neurone disease, HIV and Parkinson's disease (British Lymphology Society (BLS), 2017).

The fact that lymphoedema services are under-resourced and unevenly distributed across the UK, and may even be absent in some areas, further exacerbates the situation (Brown and Sneddon, 2020). Timely diagnosis and management of lymphoedema can make a significant impact on the person's quality of life.

This document aims to raise awareness regarding early identification of lymphoedema and provide information on what all healthcare professionals can do to start the management early on to avoid complications. This is essential so that patients do not have to wait for referrals to lymphoedema services to begin basic management techniques that any healthcare professional can initiate.

Empowering and educating the patient is key to effective management. By establishing long-term partnerships with patients, healthcare professionals can improve outcomes. The more the patient understands and looks after their lymphatic system, the better the outcomes of all other treatments. This document, intended for all primary care professionals, contains important information regarding:

- Lymphoedema and its symptoms
- Management strategies
- The role of all healthcare professionals
- Patient involvement and empowerment
- How to find lymphoedema services in your area and what to do if there are no services in your area?

This document is intended for all healthcare professionals working in primary care, from GPs to practice, community and district nursing and other primary care services including healthcare assistants, social prescribers and proactive care teams.

Immediate actions that can be taken by all healthcare practitioners

- Identify the signs and symptoms of lymphoedema (see page 16)
- Initiate first aid immediately (skin care, movement, positioning) (see page 17)
- Check for red flags (see page 16)
- Refer onwards (see page 21)

Introduction

Lymphoedema is a common chronic condition arising from the failure of the lymphatic system resulting in protein-rich fluid buildup (Sanka et al, 2025). It causes swelling in body parts including the legs, arms, neck and genitals. Chronic oedema offers an umbrella description of persistent oedema, including lymphoedema, affecting any part of the body for more than 3 months regardless of its cause (BLS, 2023a).

With early diagnosis, lymphoedema management is likely to be less costly and improved patient outcomes more successful. If left untreated, lymphoedema is likely to worsen over time, causing considerable physical and psychological distress and impact on activities of daily living and employability (BLS, 2019).

However, not enough people recognise lymphoedema early. The duration of time that people have to wait in order to get the appropriate management can be a lengthy process. Patients may have to wait 10–15 years (Mitchell et al, 2019) for a diagnosis in some cases and by then, it is already much more difficult to treat or manage because the condition has typically progressed significantly.

Within primary care, management pathways for this patient group are predominantly delivered through community nursing teams or specialist lymphoedema services. Evidence suggests that practice nurses are well placed to provide early intervention, particularly for ambulant patients; however, this aspect of care is not routinely commissioned within community services, leading to a significant unmet need (O'Neill, 2019).

Early recognition of lymphoedema by primary care practitioners could reduce delays in access to first aid lymphoedema care. It is important to recognise that it is about an ongoing relationship to manage these individuals with lymphoedema, a partnership that is going to be lifelong in the vast majority of cases.

For information on lymphoedema services in your area, or what to do in the absence of these services, please visit (please note that the BLS directory only lists member services):

- https://www.thebls.com/directory
- https://www.thebls.com/pages/professional-and-patients

Goal setting and partnership working

The key goal in effective lymphoedema management is patient engagement, as well as empowering them with knowledge, skills and confidence to manage their health and make informed choices. Long-term engagement and understanding are important for successful outcomes.

A patient may be labelled as non-concordant, but the issue may simply be a lack of understanding about their care plans or prescribed interventions.

Compression is a common example where the prescribed garment may be inappropriate for a patient's specific needs and thus result in non-adherence.

It is important to recognise these situations as opportunities to improve communication, ensure comprehension and tailor treatments to align well with the patient's needs. By shifting the focus to patient empowerment and education, adherence and outcomes can be improved in chronic care.

A proactive approach will upskill the patients to try and reduce the risk of difficult complications and allow them to successfully manage their condition (Allegrante et al, 2019) with much less reliance on the healthcare system, without adding to the existing burden of healthcare practitioners.

The burden of lymphoedema across the UK

While studies carried out in 2003 suggested that there were at least 100 000 individuals living with lymphoedema in the UK (Moffatt et al, 2003), based on the most recent population figures, it affects nearly between 265 000 and 456 500 people of all ages in the UK (BLS, 2023a).

Data from referrals to the national lymphoedema service in Wales reveal a prevalence of 6.67 per 1000, and in Northern Ireland the prevalence is 6.78 (BLS, 2023a). This has significant implications for patients' quality of life and healthcare services in the country.

Due to the lack of available local lymphoedema services, care needs to be shifted to the wider generic healthcare workforce, which may dilute or reduce care quality and exacerbate lymphoedema outcomes.

Moffat et al (2003) found that among 823 lymphoedema patients:

- 27% required hospital admission for antibiotic treatment
- 32% needed compression bandaging
- 29% had cellulitis in the past 12 months
- 80% had to take time off work and 8% had to give up work completely.

The mean length of hospital stay for these patients was 12 days, and the mean cost was £2300 (Moffat et al, 2003).

Precise national incidence and prevalence data remain limited, though local data collected through primary care networks and specialist services indicate a rising number of cases. This shift highlights the need for greater awareness for earlier identification. There is also the need for improved pathways within primary and community settings.

The economic burden of lymphoedema is also considerable. This includes recurrent cellulitis, unplanned hospital admissions and prolonged treatment costs.

The urgent need for strategies for early recognition and evidence-based management for reducing the risk of lymphoedema is evident from this data. Lymphoedema is not curable, but it can be managed with timely intervention. UK-specific data are needed to guide commissioning decisions and service development. This will help to reduce long-term strain on the NHS.

Why all healthcare professionals are critical

Your role in lymphoedema care

All healthcare professionals have a responsibility to recognise and understand lymphoedema in order to work with patients during their journey to improve their outcomes, overcoming challenges along the way. Early recognition of lymphoedema and its management cannot be attributed to a single service. In some cases, lymphoedema services may not be available in the area. Even when these services are present, their capacity is limited. Referral to lymphoedema services does not constitute an immediate resolution of the condition. It is simply one part of a comprehensive and long-term management strategy.

The annual direct costs associated with cellulitis for NHS Wales are over £28 million. When extrapolated for the UK, this amount comes to over £571 million (Humphreys et al, 2023). Cellulitis cases have increased three-fold over the past 15 years (UK Parliament, 2013).

Hospital admission costs for cellulitis in Derbyshire, Nottingham and Lincolnshire were approximately £4.1 million in one year for these areas (UK Parliament, 2013).

The key to improving lymphoedema care is through the empowerment of healthcare professionals and generalists in primary care. This will initiate early management and prevent ongoing development and complications. This aligns with messages from the National Wound Care Strategy (Legs Matter, 2025): early intervention is crucial and can result in reduced hospitalisations.

However, sometimes practitioners may simply feel that the condition is outside their expertise or responsibility. Rather than dismissing or ignoring it, it is important to flag it. A hands-off approach leaves gaps in care with severe consequences such as cellulitis and ulcers.

A shared-care approach is essential as well to involve those working in social care and roles like social prescribers. Many patients face challenges accessing support and these professionals can play a huge role in identifying lymphoedema early. Education and awareness across the whole community multidisciplinary team is key.

Patients must also understand what they can do themselves, without the support of healthcare professionals, to manage their condition, including movement, weight management and skin care (refer to the First Aid section for more information).

Lymphatic system fundamentals

Lymphoedema arises when the lymphatic system fails to fulfil its function of regulating fluid balance in tissue spaces. This results in swelling and causes changes in the skin and subcutaneous tissues.

The lymphatic system is composed of lymphoid organs, lymph nodes and an extensive network of

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vessels (Figure 1) (Sneddon and Elwell, 2020). Its primary physiological functions include immune surveillance, nutrient transport and fluid homeostasis.

Dietary fats and fat-soluble vitamins, including vitamin K, are absorbed by the lymphatic system, which also manages the drainage of interstitial fluid. The lymphatic system relies on muscular movement, respiration and fascial tension to move lymph through the vessels (Rossitto et al, 2019).

To maintain lymphatic health, Sneddon and Elwell (2020) advocate simple but crucial interventions. These include:
- Regular movement to activate lymphatic flow
- Skin protection to prevent cellulitis
- Weight management to reduce extra load or pressure on the lymphatic system.

> Lymphatic flow can increase up to 20-fold under pathological conditions like inflammation or chronic venous insufficiency, although this compensatory mechanism is not indefinitely sustainable (Sneddon and Elwell, 2020).

Skin integrity is particularly important. Damage to the skin can lead to inflammatory responses or cellulitis, especially in older adults or those with compromised lymphatic function (Woods, 2019; BLS, 2022). When the body fails to properly drain excess fluid from tissues, it can lead to lymphoedema, causing swelling, inflammation and thickening of the skin and tissues over time.

Early signs include cellulitis and skin changes. In venous insufficiency, venous hypertension can lead to

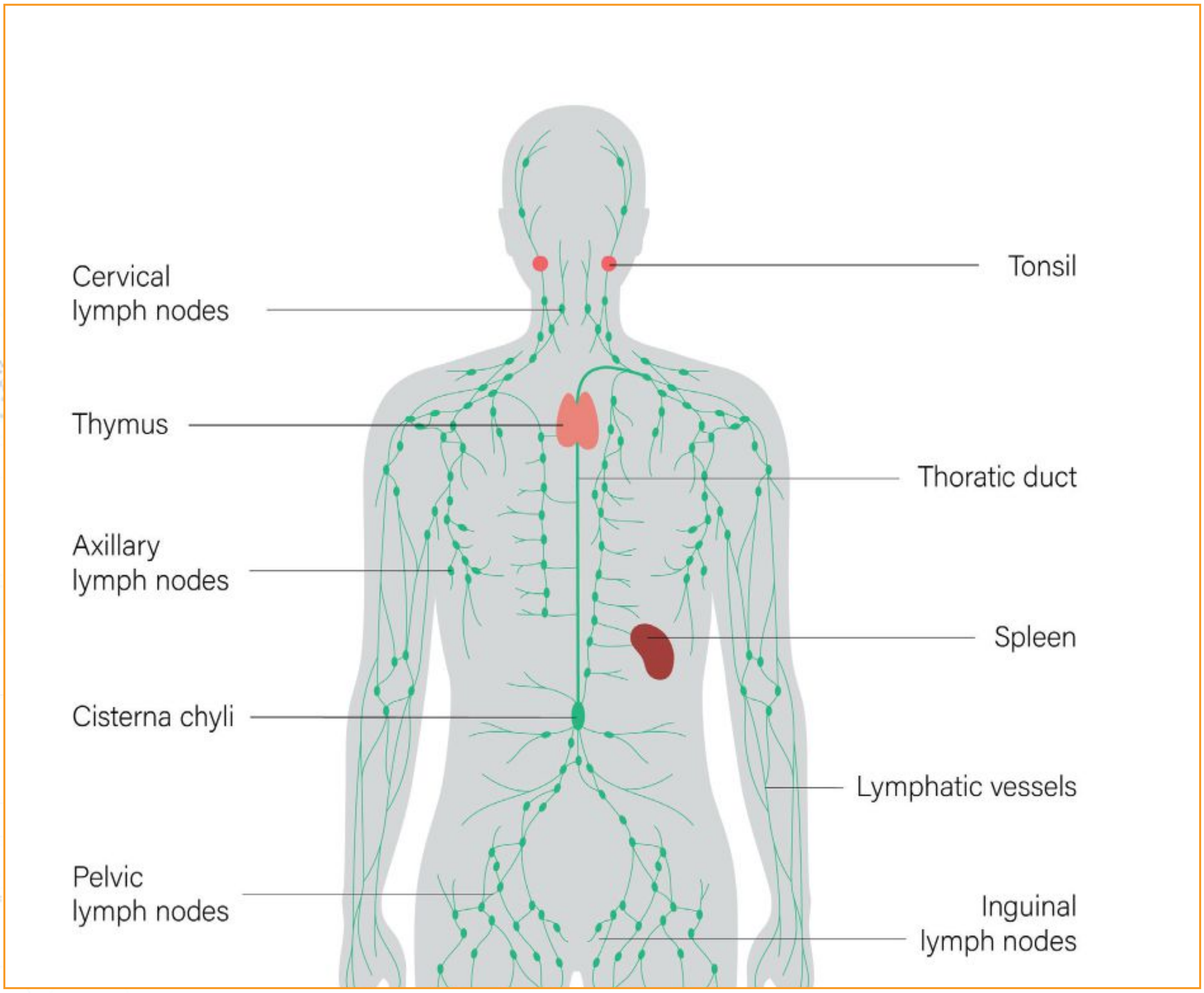

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Figure 1. The lymphatic system of the body.

haemosiderin staining and ankle flare, and while lymphatic dysfunction may contribute to oedema, it is not the direct cause of these skin changes (Sneddon and Elwell, 2020).

Disruptions to the normal lymphatic function of the body can affect multiple systems in the body. These manifest as varied pathologies and conditions related to lymphatic dysfunction in all body systems, including heart failure and renal diseases (Mehrara et al, 2023).

Sung et al (2022) found that a series of events impact the pathology of lymphoedema, which include lymphatic stasis, the formation of leaky lymphatic vessels, chronic inflammation, adipose tissue deposition, fibrosis and progressive loss of functional lymphatics. A deeper understanding of these mechanisms could facilitate the development of more effective therapeutic strategies.

Barriers to lymphoedema care

By advocating preventative management, primary care practitioners can reduce their work load. However, barriers such as lack of training, ineffective teamwork and unclear responsibility make this difficult (Endalamaw et al, 2024).

For lower limb cellulitis and care related to it, community nurses described time constraints and difficulty navigating complex systems (such as arranging Doppler assessments, supply orders) as barriers to implementing compression and skincare interventions (Muller et al, 2024).

There are also many 'myths' regarding lymphoedema (Appendix 1: Myth busters).

Lack of role recognition

One of the biggest barriers may be that healthcare professionals do not recognise or realise that they have a responsibility or role in identifying and managing lymphoedema.

Historically, lymphoedema management has been seen as a specialist role, but with changes to understanding and an increase in chronic illnesses, lymphoedema should be recognised as every healthcare professional's role to deliver immediate and necessary care (Level 1 lymphoedema first aid) and for those with additional training (Level II first aid), which includes assessment of the cause and exacerbating factors, and initiating compression therapy for patients with lymphoedema.

Understanding why the role of primary care practitioners is so important

While it must be acknowledged that all healthcare professionals and services are busy, there are tremendous pressures on community nursing teams, especially with the 10-year long term plan focussing on moving more care to the community (NHS England, 2025). The district or community nurse may not visit lymphoedema patients until it is already too late to effectively manage the symptoms. The aim of this document is to stimulate change in lymphoedema identification and management. One informed GP who ends the hands-off approach to lymphoedema management can have a ripple effect, impacting meaningful changes in practice. All healthcare practitioners should be proactive when reviewing every patient and make every contact count (NHS England, 2016).

In reality, it is about understanding the underlying causes or the factors affecting the outcome of any treatment. For instance, simply applying a dressing to a wet leg in an attempt to contain exudate is ineffective without recognising the underlying science that in fact compression is required to stop lymphorrhoea.

Without formal recognition, district or practice nurses may not perceive garment fitting as part of their remit. The On the Ground Clinical Lymphoedema Education Programme for Community Staff (NHS Wales, 2024) initiative in Wales addressed this by embedding lymphoedema training into community nursing, demonstrating the value of compression garments in the management of lymphoedema and wound healing, along with reducing visits compared to the application of bandaging.

It positively impacted patient care: increased compression levels (36%); patients switched to compression garments, reducing nurse visits (25%); received garments for proactive care (19%). There was also an improvement in staff competence and confidence, and there were significant overall cost savings (NHS Wales, 2024).

Lack of training and education

Lack of training and education are often cited as additional barriers to lymphoedema management but free GP training has been available through the Royal College of General Practitioners (RCGP) (2016) to its members and GP registrars since 2016. The course educates on lymphoedema diagnosis, causes and management. Healthcare professionals who are not RCGP members can access the course for a fee.

The Lymphoedema Support Network has also developed a lymphoedema module in conjunction with the British Medical Journal for GPs and other healthcare professionals. The module is available at: http://learning.bmj.com/learning/module-intro/lymphoedema-.html?moduleId=10029385

Lack of knowledge about bandaging

Another common barrier is the knowledge surrounding lymphoedema bandaging. The chronic oedema wet leg pathway (Lymphoedema Wales, 2022) is a valuable resource for healthcare practitioners who are hesitant to use bandaging (Appendix 2: wet legs pathway and management plan).

Unfortunately, lymphoedema, lymphology and the lymphatic system are not taught at a detailed level at undergraduate level, often leading to a lack of knowledge that may continue for many years or even a lifetime.

This oversight has also added to the perception that lymphoedema management is exclusive and treatment needs to be provided by lymphoedema specialists only, which limits the involvement of other healthcare practitioners.

The Lymphoedema Network Northern Ireland (2022) offers essential resources on how we can increase the knowledge of lymphoedema among patients and healthcare practitioners, including compression bandaging precautions and other treatment and support (Appendix 3: lower limb inflammatory pathway).

The Chartered Society of Physiotherapy (CSP) has advocated for lymphoedema teams, including physiotherapy staff, to incorporate educational responsibilities within their roles and that healthcare professionals working with 'at-risk' populations should receive targeted awareness training to enhance diagnostic accuracy and familiarity with referral pathways. The CSP has also published guidelines on what anyone within physiotherapy can do for lymphoedema diagnosis and management.

Commissioning inconsistencies

There are different commissioning models for lymphoedema throughout the UK, with some areas having no specified pathway. This can leave practitioners not knowing where to go for help or where to find out about services locally. This can lead to delays in diagnosis and increased risk of complications.

Lymphoedema services in the UK operate from a variety of settings: acute or community hospitals, health centres, GP surgeries, hospices or locations arranged independently. The majority of services are funded through the NHS, though some therapists providing treatment also operate privately across the UK. The level of care within services varies and often funding limits what may be considered as optimised care.

Variances between England, Northern Ireland, Scotland and Wales exist in the procurement process, the structure of funding and the tariff payment for lymphoedema services.

In England, the commissioning is complex and ever evolving, especially now with the new NHS structure laid out in the 10-year fit for the future plan.

There is no national tariff payment system for lymphoedema in England and, therefore, tariffs are agreed locally. In Northern Ireland, lymphoedema services operate throughout the 5 Health and Social Care Trusts and are provided from general and community hospitals. There is no national tariff as service funding is based upon block annual budgets related to catchment area population (BLS, 2021).

Lymphoedema Wales Clinical Network (LWCN) is funded by NHS Wales and delivers lymphoedema services across all seven Health Boards in Wales, supported by a dedicated National Team. The service provides comprehensive care for both adults and children living with primary and secondary lymphoedema.

LWCN is a multidisciplinary network, comprising nurses, physiotherapists, psychologists, researchers, and a dietician, reflecting a holistic and patient-centred

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approach to care. In addition to clinical services, the National Team also leads the National Cellulitis Improvement Programme, a proactive initiative aimed at reducing the risk and recurrence of cellulitis through education, risk reduction and early intervention. Visit https://lwcn.nhs.wales/ for more details. Patients can also self refer in Wales. All health board contacts are available on the BLS website https://www.thebls.com

In Scotland, the framework of provision is similar to England, with lymphoedema services being funded by 14 regional NHS health boards (BLS, 2021).

The lack of consistency and clarity in commissioning models for lymphoedema services across the UK underscores the need for clear national guidance and accessible referral directories.

A standardised commissioning framework will support integrated care and ensure timely access to specialist services for patients. A quick guide to finding local services in your area: https://www.thebls.com/directory

Lack of patient partnerships

The key to success and good outcomes is the patient. Patient empowerment is absolutely fundamental. Patient goals may be simple, such as improving walking, whereas service goals may be reducing incidence of lymphorrhoea or cellulitis to relieve burden on services.

Healthcare practitioners can help to build understanding by explaining the purpose of compression, and the differences in wraps systems and fabric types (eg flat-knit vs circular-knit).

For patients with severe or irregular limb shapes, flat-knit garments are generally recommended. This is because these often provide higher containment and stiffness (International Lymphoedema Framework, 2019).

> You can support lymphoedema management by educating the patient on simple things such as explaining the importance of gravity in limiting the return of fluid, and supporting the patient in being able to get into bed or a recliner chair. This may help to improve the symptoms with very little intervention over a consistent time.

Bandaging should be considered for irregularly shaped limbs, depending on the level of deformity and the wrapping and padding needs.

Circular-knit garments are generally more elastic and may be better for milder cases (International Lymphoedema Framework, 2019).

Addressing and dispelling myths is also an important part of the job for all healthcare practitioners. Flat-knit garments may appear thicker, which is why people often think they are difficult to use. In fact, these are often easier to apply and more tolerable due to structural stability, consistent pressure distribution and lower possibility of causing skin folds or constriction.

The misconception can lead to resistance from the patient when a clinician suggests a flat-knit garment, which may be the most appropriate.

Flat-knit garments can offer containment without relying too much on elasticity, which may make them more effective for some patients.

You can help patients to identify the signs of poor fitting garments

These include rolling, digging into the skin, or tightness. Regular monitoring of limb measurements ensures that compression garments fit correctly and can be adjusted or replaced when necessary.

> You can reassure patients about the feel of the compression garment.
>
> A feeling of firm support or gentle pressure is to be expected but these garments should never cause pain or significant discomfort.
>
> If there is any pain, numbness or skin irritation, they need to stop using the garment and talk to the relevant healthcare professional.
>
> It may be a result of incorrect sizing, improper application or complication such as infection or deep vein thrombosis (International Lymphoedema Framework, 2019).
>
> Useful link: Patient information leaflet on compression hosiery https://www.royalsurrey.nhs.uk/download.cfm?doc=docm93jijm4n20356&ver=50136

Since limb size may change over time, ongoing observation by the patient themselves is essential. Where the patient has capacity, it is important to give them the knowledge and understanding to be able to identify when their garment does not fit well and they should know how to contact the clinician.

Most services cannot resource routine reviews for patients. Empowering the patient will allow them to take control and be in charge of their condition. As they are the ones living every day with lymphoedema, they are much more knowledgeable about any changes to the affected limb.

- Supporting patients in differentiating between normal and concerning sensations can promote adherence to compression
- Clear and practical advice regarding donning and doffing of garments is essential
- This can significantly improve patient involvement for people with reduced mobility or dexterity
- Many products designed to assist in the application of garments are available by prescription.

NHS systemic challenges

Different teams communicate with different electronic systems and it can be extremely challenging to join the dots. Electronic patient records are not shared across the NHS. Lymphoedema services are often standalone, within a hospice, within a care system, within acute trusts. They have no way of looking at the patient records in primary care.

Electronic prescribing can complicate custom orders; it important to ensure that all codes and measurements are accurate. Communication between teams is essential and it needs to be established locally. With the NHS 10-year health plan focused on moving from paper-based systems to digital solutions, there is hope that healthcare practitioners will have better access to patient records across systems (NHS England, 2025).

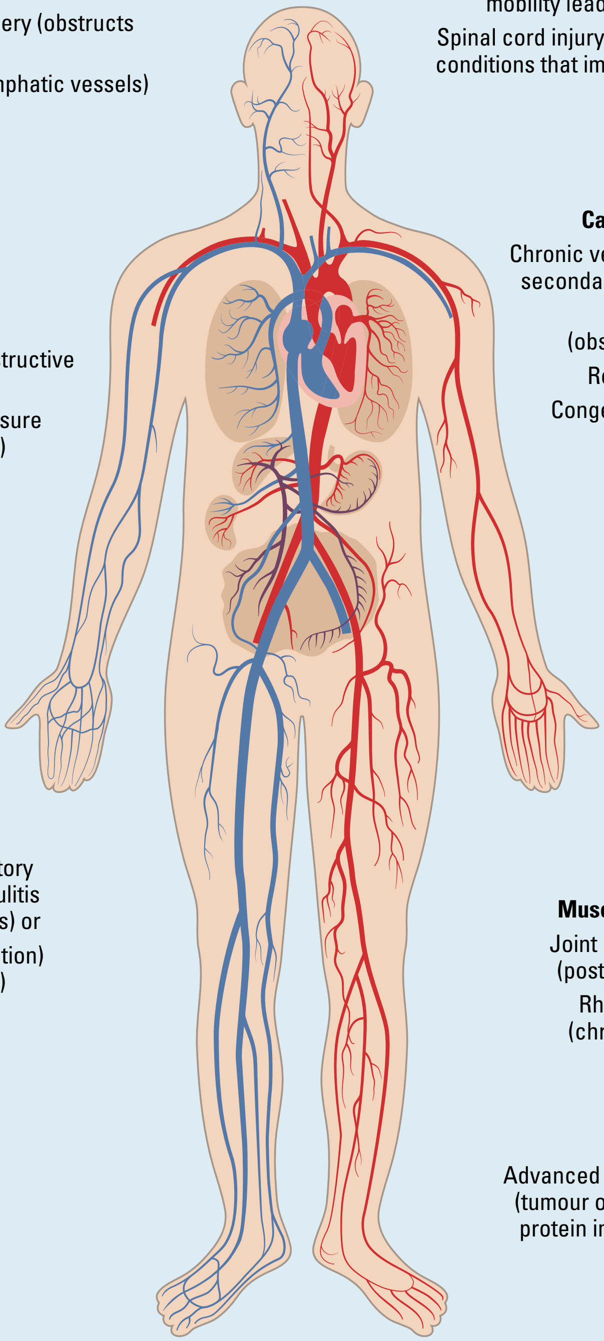
Patient advocacy is crucial. It is important to emphasise early recognition and referral to reduce escalation of symptoms and improve quality of life.

Table 1. Risk factors for lymphoedema

Direct risk factors	Indirect risk factors
Damage to or malformation of lymphatic vessels (congenital or acquired)	Obesity (increases lymphatic load)
Lymph node removal (surgery)	Reduced mobility or immobility
Radiotherapy	Chronic venous insufficiency or deep vein thrombosis
Malignancy obstructing lymphatics	Recurrent cellulitis or infections
Trauma damaging lymphatics	Advanced age; immunocompromised
Severe infection damaging lymphatics	Poor skin care or unmanaged wounds

Box 1. Causes of secondary lymphoedema

- Cellulitis
- Obesity and reduced mobility
- Inflammatory conditions that may impair the small lymphatic vessels, such as chronic skin conditions, wounds, particularly if healing is prolonged, untreated fungal infections, inflammation following insect bites or stings
- Conditions that cause more fluid to leak into the tissues of the body, such as varicose veins, deep venous thrombosis, heart failure
- Surgery that removes or damages areas where there are lymph nodes and vessels, such as cancer of the breast, pelvic area, melanoma, head and neck cancer
- Treatment such as radiation that affects lymphatic collectors
- Orthopaedic and other surgeries carry a risk, especially if there is an unknown cause of primary lymphoedema
- Conditions that inhibit mobility and activity, such as stroke, multiple sclerosis and frailty
- Some medications, such as calcium channel blockers used to treat hypertension, especially amlodipine. Others include corticosteroids, non-steroidal anti-inflammatory drugs and sex hormones.



Lymphatic system

Primary lymphoedema (congenital malformation)

Lymph node removal/surgery (obstructs drainage)

Radiotherapy (damages lymphatic vessels)

Respiratory system

Chronic asthma/chronic obstructive pulmonary disease

(increased thoracic pressure obstructs lymph flow)

Liver disease

Protein imbalance (can result in swelling)

Skin

Infections or inflammatory conditions such as cellulitis (damages lymph vessels) or

filariasis (parasitic infection) blocking lymphatics)

Nervous system

Stroke or multiple sclerosis (reduced mobility leads to fluid stasis)

Spinal cord injury or other neurological conditions that impair the muscle pump

Cardiovascular system

Chronic venous insufficiency (leads to secondary lymphoedema) and deep vein thrombosis

(obstructs lymphatic flow)

Reflux, varicose veins

Congestive heart failure (fluid overload)

Hypertension

Renal system

Chronic kidney disease is a contributing factor

Musculoskeletal system

Joint replacement surgery (post-operative swelling)

Rheumatoid arthritis (chronic inflammation)

Palliative

Advanced cancer or end-stage disease (tumour obstruction, fluid overload or protein imbalance leads to swelling)

Figure 2. Conditions contributing to lymphoedema.

Goal setting can ensure appropriate management and education, and partnership working will empower the patient. They will be informed about supported self-management, knowing when to dip back into the services for assistance.

Causes and risk factors

Primary vs secondary lymphoedema

Primary lymphoedema usually stems from genetic factors (such as Milroy's disease, caused by mutations in the FLT4 gene [VEGFR-3]), and results in chronic swelling when the lymphatic system fails to drain fluid properly (Gordan et al, 2020). These genetic factors result in abnormal formation of the lymphatic system, leading to impaired function, and the condition may not always be apparent at birth.

Link between obesity and lymphatic failure

Labropoulos et al (2023) found significant links between severe obesity and lymphoedema diagnosis, doubling from 2013 to 2019. There was also a two-and-a-half fold increase in cellulitis incidence.

Box 2. Signs and symptoms that people at risk of lymphoedema and all healthcare practitioners should look out for

- Swelling in the 'at-risk' limb or area of the body (even if this goes down at night)
- Heavy feeling or ache in the limb or area of the body
- Increasing tightness of jewellery
- Red hot area, rash or 'flu-like' symptoms that may indicate cellulitis
- Skin changes, thickening or pitted, orange peel-like texture

Primary lymphoedema is less common than secondary lymphoedema, which arises as a result of damage to a normally functioning lymphatic system. There are many causes of secondary lymphoedema (Box 1).

High-risk populations

It is important that individuals who are at risk understand what lymphoedema is, and why they are at risk. This includes those who are obese, have limited mobility or frailty, vascular disorders and chronic wounds (Figure 2) (Table 1).

People who have cancer or have undergone cancer treatments are at a risk of developing lymphoedema caused by blockage to the flow of lymph fluid, surgery or radiotherapy that causes tissue changes (National Cancer Institute, 2024).

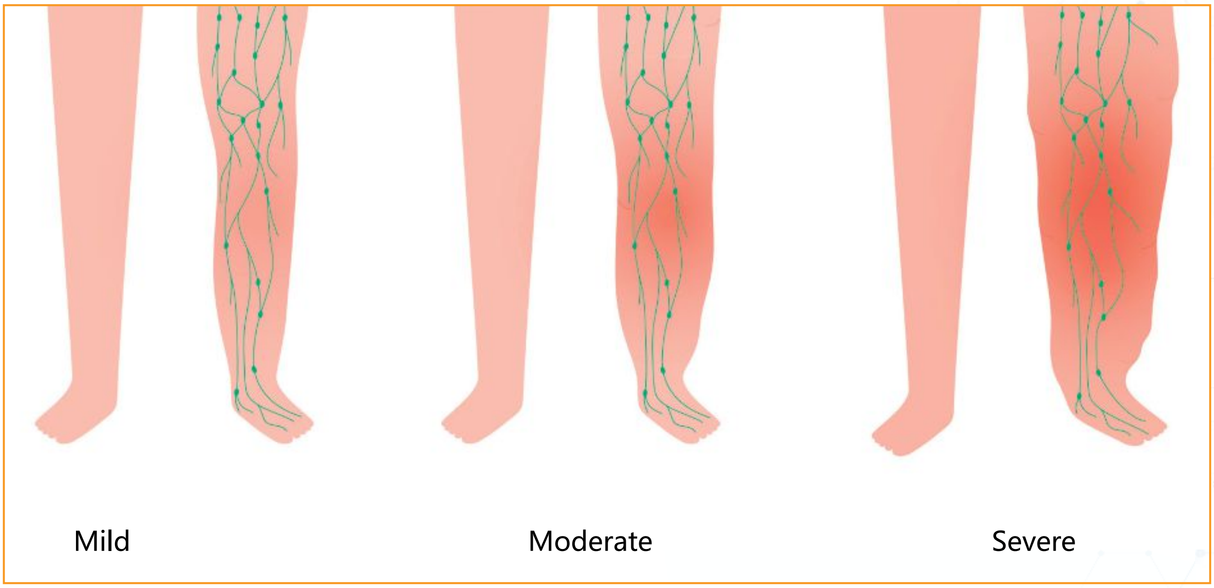


Image: Adobe Stock/hereswendy

Figure 4. Progression of lymphoedema from mild to severe.

Table 2. Red flags

Red flag	Why it matters	Action required
Rapid swelling; increased pain; localised inflammation	May indicate cellulitis or deep vein thrombosis	■ Medical review; antibiotics
Lymph leakage	Sign of uncontrolled lymphorrhoea	■ Initiate compression therapy
Fever with limb swelling	Possible infection	■ Urgent GP or hospital referral
New or worsening reduced mobility	Risk of deterioration	■ Occupational therapist or physiotherapist involvement; frailty referral; mobility support; medical management of heart failure
Breathlessness; signs of heart failure	Risk of deterioration	■ Medical management of heart failure

Healthcare professionals must make sure that patients are fully aware of the signs and symptoms of lymphoedema (Box 2) and have the relevant information regarding cellulitis.

Those 'at risk' should be given this information by a healthcare professional backed up with information leaflets (Lymphoedema Support Network, 2022; BLS, 2023b; 2023d).

Clinical presentation and progression: what to look for

When assessing lymphoedema, it is important to look at the whole limb, the tissues, the skin and the shape of the limb to check for distortion. This is very simple, does not require specialist level, and may impact management strategies. Figure 4 shows the progression of lymphoedema from mild to advanced and severe. See Table 2 for lymphoedema red flags.

Symptoms of lymphoedema

- Swelling (that may come and go)
- Tightness or fullness in any part of the body but commonly the limbs
- Pain or ache in the affected region
- Clothes or shoes feel tighter
- Discomfort when wearing jewellery
- Pitting
- Impaired mobility in the affected limb or area
- Skin and tissue thickening.

Comprehensive patient assessment

Observational assessment

Begin assessments as the patient enters, noting mobility, footwear, body type (eg obesity) and support availability.

Avoid assumptions. Patients with mobility limitations may still tolerate compression well.

> Lymphoedema can present with shape distortion through the natural disease process, but shape distortion can also be caused by treatment, eg suboptimal bandaging or hosiery choices. This may include large dorsums of feet or large knees and shoulders. Poor positioning and dependency can cause shape distortion, eg chair sleeping. Treatment plans should include addressing the underlying cause where possible. When shape distortion is present, the limb shape usually does not fit into off the shelf compression hosiery and requires made to measure garments.

The 5 S lymphoedema assessment guide: skin, subcutaneous tissues, site, size and shape

The BLS 5 S assessment guide is used during examination of the patient and enables clinicians to identify and understand clinical findings to determine severity of lymphoedema.

The findings from the 5 S clinical features can also aid understanding of the underlying cause of the lymphoedema; however, this assumes a thorough history has been taken, appropriate measurements or parameters recorded and investigations and screening where appropriate has been undertaken (BLS, 2025)

Identifying shape distortion indicates complicated lymphoedema presentation. The treatment goals should work towards correcting this shape change where possible, and maintaining the improvement thereafter.

Midline/genital oedema

The Lower Limb and Genital Lymphoedema Questionnaire for Women (LLGLQw) and Lower Limb and Genital Lymphoedema Questionnaire for Men (LLGLQm) (Lymphoedema Wales Clinical Network, 2022) are easily available to assist lymphoedema practitioners and their patients. It is important to identify and manage midline lymphoedema.

Although garments can be challenging, movement and supported self-lymphatic drainage can be very helpful. A well-fitting bra with wide straps can support breast oedema, while good quality, well-fitting underwear can help manage genital oedema.

If identified early, many patients are able to manage effectively with 'normal' supportive garments rather than medical compression.

First aid

Immediate and necessary care is important, even if healthcare practitioners are going to refer a patient on to a specialist (Table 3).

These basic strategies will be the same and will overlap with a lot of the other advice and information that they offer. For instance, sharing information about weight management and skin care need not be a separate conversation.

Table 3. Lymphoedema first aider

Level 1	**Level 2**
Any healthcare professional can do this	Professional with some experience, such as a community or practice nurse with experience in assessing for compression therapy
Skin care advice	Identify risk factors (or contributing factors) to lymphoedema in medical history and managing or signposting for management (eg directing to GP for medication review, management of hypertension, heart failure, kidney disease etc)
Positioning advice	Assess suitability for compression and instigate as appropriate
Movement and activity advice	Liaise with GP for prescription of skincare products such as emollients and debridement pads if required
Importance of maintaining a healthy weight advice	Refer on to other members of multidisciplinary team such as physiotherapy for addressing mobility problems; occupational therapists for perching stools or donning and doffing aids; or podiatry
Refer on to GP or community nursing team for addition of compression and/or referral on to specialist service, if required	Assess the need for referral to specialist lymphoedema services and refer when appropriate

Whether a person has eczema or lymphoedema, the instructions are the same: wash with a soap substitute, pat dry and apply an emollient regularly.

Encourage patients to take care of themselves and follow public health advice—stop smoking, reduce alcohol intake, monitor weight and look after your skin. These simple steps should be implemented swiftly and without delay. The UK government has published physical activity guidelines regarding the amount and type of physical activity needed to improve health: https://www.gov.uk/government/collections/physical-activity-guidelines

Skin care

Figure 3 mentions important skin care information for lymphoedema self-management. Common skin concerns in lymphoedema include:

- Lymphorrhoea: leaking of lymph fluid through the skin. Use an appropriate absorbent non-adhesive dressing and compression (See Appendix 2: The Wet Legs Pathway)
- Fungal infections: moist skin folds create the perfect environment for fungal infection. Keep the skin dry and treat with antifungals if needed.
- Maceration: prolonged moisture breaks down the skin, making it fragile and prone to cellulitis. Protect with barrier creams and keep skin folds dry
- Fissures and cracks: these occur in dry skin and are commonly seen on heels. These can be managed with emollients containing urea or prevented with regular moisturisation
- Papillomatosis: these are warty bumps from fibrosed lymph vessels. Compression can help reduce these bumps
- Hyperkeratosis: this occurs when skin becomes thick and crusty and is prone to cellulitis. Softening ointments or dressings are required to manage this condition. There are products that can help remove skin, such as debridement cloths and pads
- Cellulitis: this is a serious bacterial skin infection. Signs include redness, heat, pain, and swelling, and it requires immediate antibiotic treatment
- Scarring: These can cause stiffness and poor circulation and should be treated under specialist guidance.

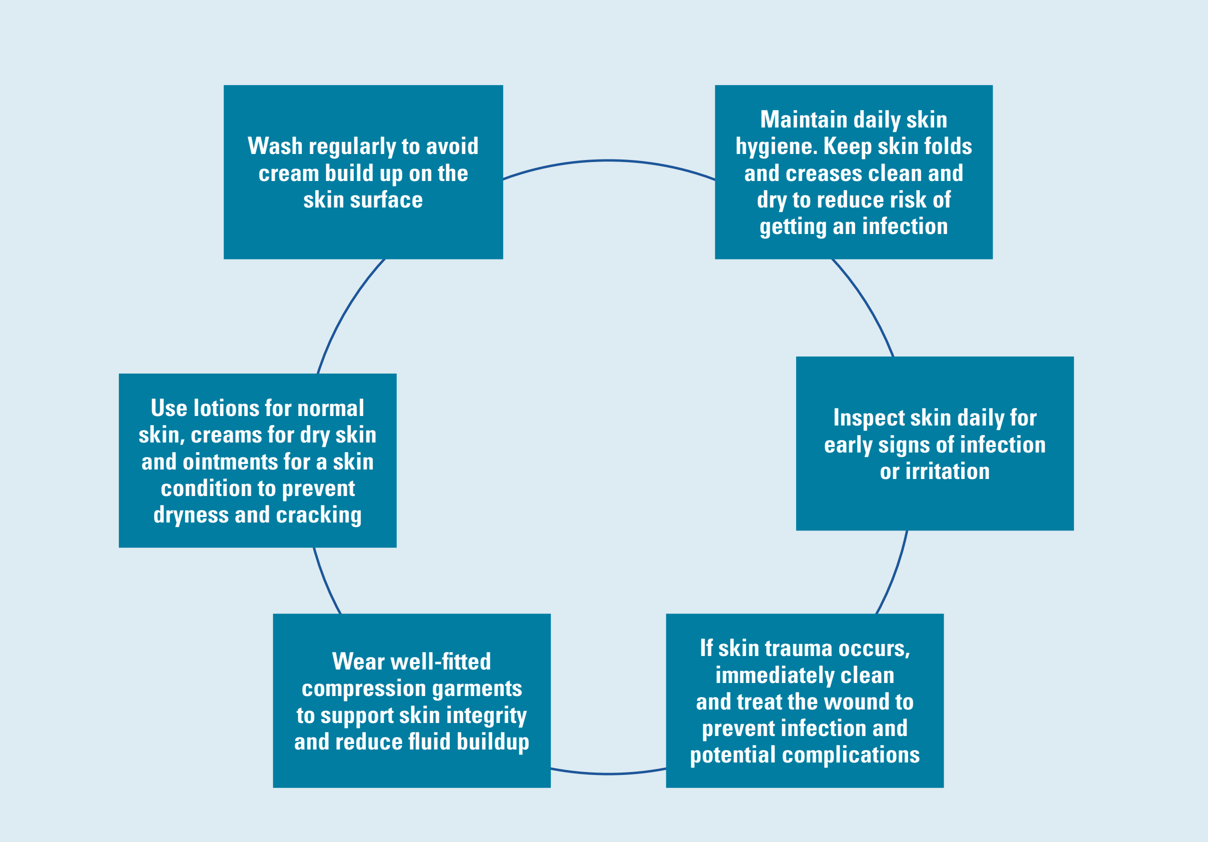


Figure 3. Skin care for lymphoedema.

- Radiation damage: it can leave the skin fragile and stiff with a reduced ability to heal. Ongoing specialist input is essential.

Specialist advice may be needed for:

- Chronic or severe skin changes
- Nail infections or foot issues (refer to podiatry)
- Suspected chylous leaks (require specialist dietary advice)
- Keloid scars (should not be massaged).

Preventative care

- Educate patients on skin care
- Use soap substitutes and barrier creams for sensitive or broken skin.

Movement

Activity is one of the cornerstones of care in the management of lymphoedema. It has a role in treatment regardless of the patient's age, ability or the severity of their condition.

Movement is important to minimise risk and at all points along treatment pathway. It should also be incorporated into the patient's supported self-management programme in the maintenance phase. In the case of patients with paralysis, passive exercise is recommended as it is believed that this may increase the contractions of the intrinsic pump.

Most patients are able to engage with beneficial activity if time is taken to explore what is meaningful and enjoyable for them and what can be built into their daily routine, especially if supported by visual material — written and pictorial leaflets, videos or apps. Being able to direct people to helpful online or mobile apps and resources will support engagement (see thebls.com).

Traditionally, those with, or at risk of, lymphoedema were strongly advised to avoid weightlifting or

Regardless of the site of lymphoedema, the following exercises may be recommended:

- Swimming or aqua aerobics
- Yoga and pilates
- Tai chi and qi gong
- Nordic walking and any other type of brisk walking
- Set programmes of strengthening exercise which include active movement or isotonic activity
- Gym work
- Any additional preferred activity for general fitness, eg dancing.

Before giving your patients any exercises ensure you have assessed their ability to undertake the exercises and that you give a leaflet or electronic resource to refer back to when they are at home (See Appendix 7).

Tell your patients about the BLS 'find 3' challenge

The best way to help your lymphatic system to do its job is to have short, regular periods of activity that can easily be built into your daily life. That's why we are asking you to 'Find 3 Minutes' at various times throughout the day when you can do something to wake up your lymphatic system and help it to get your lymph moving. Even if your mobility is limited or need help to move any part of your body there are things you can do.

So, when could you 'find 3' to boost your lymphatic system?

Anytime you are waiting for something to happen you could be giving your lymphatic system a boost, eg waiting…

- for the kettle to boil
- on hold on a telephone call
- in your car for lights to change
- for a large document or website to download on your PC
- in a queue
- during the adverts on TV programmes
- for the microwave to ping
- for the toast to 'pop'up'.

If you spend a lot of time in one position, such as on a computer, tablet or phone, or just watching TV, make set times to get up and move around a bit or stretch your muscles, ideally every hour. Set yourself an alarm as a reminder or put a sticky note on your fridge door encouraging you to have a stretch every time you open the door to take something out. Instead of just waiting, here are a few things you could do (Caution – Never force a stretch beyond what is comfortable for you).

- Heel raises
- Calf stretches
- Knee lifts
- Deep breathing.

Case study

Patient consent was obtained for sharing this case study.

It is important to consider how engaged a patient is with their own health and self-care. You may give all the right advice but the patient may not be able to take it on board or make the required behaviour changes. Health coaching to agree management priorities and arrive at shared decision making, combined with a slow, gentle approach, seeking to identify one or two behaviour changes at a time might be essential to achieve any progress as this case study illustrates.

Jack, a 30-year-old man, worked at home on his desktop computer full time and after work, moved to his own computer to enjoy gaming. He often sat at his desk for more than 12 hours at a time, only moving for bathroom breaks. He lived at home with his parents, who did all the household chores and even cooked for him. He often took his meals at his desk.

Jack had a body mass index of 70+ and had extremely swollen lower limbs. He was worried about his health and the condition of his legs and he wanted to see improvements; however, he had not been able to make any significant changes to his lifestyle to this effect.

Jack was invited to participate in a HOPE course, which enabled him to meet online with others with the same condition as him and spend some time focussing on his wellbeing and supported self care.

Part of this programme is identifying behaviour change that is important to the person and committing to achieve smart goals they feel are realistic for them to achieve in this area. Jack understood that he needed to move more so he purchased a health monitor wrist device that would sound an alarm every 30 minutes to tell him to move.

The impact of this was enormous as he began to move regularly when prompted by the device. His weight reduced significantly and his swelling improved. Focussing on the key issue of not moving much and identifying a method of helping himself address this, proved to be the key to unlocking Jack's engagement with supported self-care and achieving improvements in his condition.

strenuous exercise. However, systematic reviews (Hayes et al, 2022 ; Wang et al, 2022) found no evidence of harm from several forms of exercise, including aerobics, resistance, yoga, qigong and pilates. These studies also reported a wide range of benefits including improvements in quality of life, strength, body mass index, mental health, and reduced pain and lymphatic swelling (Panchik et al, 2019).

Positioning

With lymphoedema, it is important to counteract and minimise the effect of gravity. Elevation is key as it helps to limit fluid buildup in the limb and thus reduces swelling. For ideal lymphatic drainage, when resting, always neutralise gravity by elevating the affected limb.

Simple adjustments can go a long way.

The bed should be at an appropriate height, and the use of firm surfaces and positioning pillows can help with elevation. Patients should also be taught safe transfer techniques to enhance comfort and safety.

Prolonged sitting in a chair without adequate support can exacerbate oedema. Patients should be encouraged to avoid leaving the legs hanging for extended durations. A footrest or support should be used when possible.

Gentle movements and ankle exercises when sitting can facilitate lymph flow and prevent stiffness in the limb.

Chiropody and footwear

One of the main reasons patients present at primary care is because they cannot get the shoes on. They may not get referred to specialist services (such as podiatry or lymphoedema clinics) and may not be able to get assistance with nail cutting in the vast majority of areas.

Well-fitted and comfortable footwear not only improves mobility but also helps to avoid

Top tips to share with patients to make shoes more comfortable

1. Does the shoe have a removable insole?
If so, remove but give these back to the patient as they may need them in future

2. Can the upper of the shoes be opened?
If so, loosen the laces to bring the upper apart to open the shoe

3. Consider re-lacing the shoes
The top eyelets are the most important. Missing out some of the eyelets can open the facing of the shoe making it wider

4. Does the shoe have Velcro fastenings, but they do not fasten?
If so, consider getting extenders

5. Difficulty doing up laces?
Consider elastic laces

6. Is the sole of the shoe flat?
If so, recommend a rocker sole or heel pitch.

complications such as skin breakdown and infections. It can also reduce swelling.

When should you consider referring a patient on to specialist lymphoedema services

Patients may be referred to specialist services when:

- You have been unable to establish patient in appropriate compression
- You have not been able to make adequate progress with symptom management
- Patient has been struggling to engage with lymphoedema management
- There is very severe swelling (see the section on clinical presentation and progression: what to look for), significant skin, tissue and shape issues
- There is upper limb and midline oedema such as head and neck, breast and genitals or digit involvement, where you are unsure of options for management
- Primary lymphoedema is suspected, especially with children and young people
- Complex comorbid conditions are impacting on ability to treat (complex comorbid conditions need to be addressed where possible).

For individuals with cancer, oncology teams should provide the information before treatment and ensure prompt referral can be made to a lymphoedema service if required. Ideally the oncology team would be able to provide initial advice about managing lymphoedema symptoms and manage anxiety and expectations.

If there is no specialist service in your area...

A referral to a lymphoedema practitioner can be very difficult. If the swelling is related to a cancer diagnosis then it should be possible for you to access specialist NHS treatment for your patient.

If the condition is unrelated to a cancer diagnosis, it can be even more challenging to find an appropriate service to refer to. To find out where your local specialist is please view the BLS directory (https://www.thebls.com/directories) and click on your region.

Additionally you can email or telephone the Lymphoedema Support Network, who hold a comprehensive list of specialist lymphoedema services in the UK (please specify whether your patient has cancer or non-cancer related lymphoedema) (Lymphoedema Support Network, 2025).

If there is no service in your area please go to the section: 'There is no specialist service in my area – what can I do to help?' (https://www.lymphoedema.org/healthcare-professionals/no-specialist-service-in-my-area/)

In the event that you are unable to access specialist care through these routes, the Lymphoedema Support Network advises the following:

- Initiate basic treatment as described in 'What can I do for my patient?' section on the website
- In the presence of leaking legs or wounds, contact your local tissue viability or wound care team
- Advise your patient to contact the LSN to ask for an advocacy pack – this pack contains information about how to navigate the NHS and seek care (Lymphoedema Support Network, 2025).

The Legs Matter's 10-point plan (Legs Matter, 2025) to tackle harm campaign focuses on the harm caused by inadequate care and raises awareness to improve treatment (https://legsmatter.org/resources/legs-matters-ten-point-plan-to-tackle-harm).

Paediatric lymphoedema

It is important to recognise that children at any age can be affected by lymphoedema. The majority of these cases are primary lymphoedema; however, some can have secondary lymphoedema caused by infection or trauma. The prevalence of paediatric lymphoedema is 1.2 in 100 000 people under the age of 20 years (Cordeiro et al, 2023). Most boys are

Symptoms of paediatric lymphoedema

Primary care practitioners will see children in different cases and although it is a very small number, it is important to remember that lymphoedema is present in children. It is also important to educate the parents so that they are able to recognise, or at least flag, the common symptoms of paediatric lymphoedema including:

- Persistent or recurring swelling in arms or legs
- Skin changes
- Difficulty in activities of daily living
- Infections.

Most cases of paediatric lymphoedema can be managed well with effective compression therapy and surgical interventions are not required.

affected at birth, while it is most often present in girls at puberty (Schook et al, 2011).

Children often have to undergo inappropriate or unnecessary testing for extended periods of time because of the failure of healthcare practitioners to identify it early on. Once diagnosed, children may have to wait for up to 2 years for referral to a specialist referral service (Devoogdt et al, 2022).

The BLS Children with Lymphoedema Special Interest Group (BLSCLSIG), formed in 2010, coordinates service provision for children and young people (CYP) with lymphoedema.

The group is made up of clinicians from around the UK who manage CYP with lymphoedema as part of their caseload, including representation from the two specialist centres in the UK, St George's University Hospitals NHS Foundation Trust and the University Hospitals of Derby and Burton NHS Trust. The BLSCLSIG has a directory of all services that accept referrals for children: https://www.thebls.com/documents-library/map-of-paediatric-lymphoedema-clinics-in-the-uk

Cellulitis affects nearly 10% of cases of paediatric lymphoedema (Devoogdt, 2022), which is why early diagnosis and preventive measures can make a huge difference.

Regular monitoring and checkups are essential in children as they grow up. They may need adjustment to their management plans, along with support to deal with the psychological effects of lymphoedema.

The harm of failure to recognise and manage lymphoedema

Every contact counts and all healthcare professionals have a duty to make every contact count (NHS England, 2016). The message for all healthcare professionals is to be accountable. For instance, if a practitioner has seen somebody in primary care three times, they are accountable for not picking up on this condition. A social prescriber or a social carer would not be expected to know exactly what to do beyond immediate and necessary care but if they recognise it and refer it on, even if they only tell the pharmacist, it can make a difference.

Failing to recognise leg or foot conditions can have a devastating impact on the person and the healthcare system (Legs Matter, 2023).

For the limb

Cellulitis

Cellulitis is a painful skin infection that commonly affects the skin and its underlying tissue. It is often accompanied with chills, pain and fever and the patient's mobility is significantly impacted.

Cellulitis affects approximately 1 in 40 people (Simonsen et al, 2006). Up to 50% of lymphoedema patients experience at least one attack of cellulitis in their lifetime and it is known to be recurring in two-thirds of the patients (Teasdale, 2019).

Do not assume another health care professional will identify this patient is at risk of lymphoedema.

If you are a lymphoedema first aider, you can identify lymphoedema during your time with the patient and implement immediate and necessary care (first aid). It is likely that the patients long-term outcomes will be favourable by you taking this action. If lymphoedema is detected early, the patient is less likely to experience complications such as cellulitis, and the condition is likely to be less severe.

People with lymphoedema are particularly susceptible to cellulitis because the lymphatic system is damaged and frequently does not function adequately to fight infection.

You can educate patients regarding the management of acute episodes of cellulitis.

They should contact their doctor immediately as they may need antibiotic treatment. Treatment of cellulitis in lymphoedema is very important, not only because the person may become very ill, but because lymph drainage routes risk being damaged further. In this case, the swelling may worsen and permanent skin changes, eg thickening, may result. This does not help long-term management of the condition.

Cellulitis is often confused with lower limb inflammation, which is common in people with lymphoedema but does not make the person feel unwell. The colour of the legs changes and they feel tender and warm.

Cellulitis is over diagnosed and there is increasing dependence on antibiotics to treat it, which are often ineffective when the cause of bilateral lower limb inflammation is unlikely to be acute cellulitis.

The BLS produced the lower limb inflammatory pathway (Appendix 3) to:

- Ensure correct identification of the cause of lower limb inflammation
- Minimise the number of patients receiving an incorrect diagnosis
- Reduce inappropriate usage of antibiotics and associated health risks, along with poor patient experience
- Prevent delays in effective management being implemented.

For more information, check the consensus document on the management of cellulitis in lymphoedema (https://www.thebls.com/public/uploads/documents/document-75091530863967.pdf).

Lymphorrhoea

Lymphorrhoea, often inappropriately referred to as 'leaky legs', is defined as leaking of lymph fluid through the skin. Beads of fluid may appear on the skin of the swollen area, making the skin wet, or there may be a continuous drip from the swollen area.

> The development of spontaneous lymphorrhoea represents a change in the patient's condition that has caused the tissue pressure to be higher than the skin tension can resist, and so lymph (a straw-like or clear coloured fluid) begins to leak out.
>
> As such, a holistic review of the patient's health and medications should be undertaken to try and minimise any contributing factors where possible (BLS, 2023c).

Patients or general staff often describe this as having 'wet legs', as there may not have been a specific wound or trauma that triggered the leaking. This condition can be very distressing to experience and if it is not recognised and managed early, can lead to long-term tissue damage and hard-to-heal wounds (BLS, 2023c).

Lymphorrhoea occurs when lymphoedema is not adequately managed. This most commonly occurs in in immobile, often housebound, patients. It may be associated with leg ulceration, heart failure, advanced cancer, low albumin or nephrotic syndrome and usually affects the legs. However, any part of the body can be affected, including the genitals, and some people are more susceptible to lymphorrhoea even when they are otherwise relatively well (BLS, 2023c).

It is important to act early. Check for treatable causes and encourage the patient to maintain proper skin care and use appropriate dressings. Safe compression, elevation and mobility are essential (BLS, 2023b).

Tissue changes

Noticeable changes, such as skin thickening and hardening, are common in lymphoedema. Folds and creases also develop in skin, especially in those who have been living with lymphoedema for a long time. Cracked and dry skin develops in advanced stages.

All these changes are caused by the buildup of protein-rich lymphatic fluid. Darkening of the skin and other changes to the skin colour are also common.

Papillomata are dilated lymphatic vessels, which become fibrosed and appear as firm bumps on the skin in well-established lymphoedema. It is a common skin change seen in lymphoedema and can respond well to compression therapy.

Hyperkeratosis is a thickening of the top layer of the skin (epidermis) causing a crust-like or brown/yellow plaque formation. It often harbours bacteria which can cause an odour. Treatment includes good daily skin care using an ointment to soften and remove the hyperkeratosis, as well as hydrocolloid dressings and debridement (Elwell, 2017).

Wounds

Undiagnosed and unmanaged lymphoedema can lead to severe complications. It can compromise skin integrity and predispose the patient to ulceration. Delayed wound healing is also common. Wounds and lymphoedema are frequently underdiagnosed and inadequately managed, especially when treated with standard wound care or venous leg ulcer protocols.

The integration of tissue viability services and lymphoedema services can improve patient outcomes (Stanton et al, 2024). Microbial proliferation increases the risk of cellulitis because of the accumulation of protein-rich liquid (Al-Niaimi and Cox, 2009). Recurrent cellulitis episodes may result in frequent hospitalisation.

For the person

Psychosocial

There is a close relationship between poor quality of life and lymphoedema. Social isolation and reduced mobility can have a significant impact on the person's mental health.

Physical symptoms, lack of social, family and professional support, time-consuming daily lymphoedema care, lack of public sensitivity to the problem, insufficient health insurance and financial burdens are all factors that have a major psychosocial impact on patients (Palmer, 2025). A systematic review by Bowman et al (2020) found that cancer-related lower-extremity lymphoedema has a negative impact on quality of life and psychosocial wellbeing (Kitaw et al, 2025). Lower limb lymphoedema also contributes to higher rates of mental depression. Another systematic review (Cooper-Stanton et al, 2022) found that men faced challenges in accepting and managing their lymphoedema and it impacted their overall mental wellbeing.

Economic burden

The economic burden of lymphoedema for patients can be significant (Jaszkul et al, 2023). This includes productivity losses, as they often have to miss work, ongoing treatment costs and other out-of-pocket expenses (De Vrieze et al, 2021), such as the need for new and specialist garments and physiotherapy. In contrast, when patients are educated on self-care and self-management strategies that do not interfere with the activities of daily living, complication-related costs for the patients are significantly reduced (Karaca-Mandic et al, 2023).

For the NHS

The chronic nature of lymphoedema, and the potential for complications, means it can place a significant burden on the NHS and the workforce. This puts a strain on resources and can cause increased absences among staff. Nearly £15.48 million is spent on compression garments in England and Wales every year (LSN, 2019).

Funding a lymphoedema service can reduce inefficient spending and improve outcomes. Humphries and Thomas (2017) found that there was a considerable cost burden of lymphoedema for NHS Wales and there was the potential for cost saving when people with lymphoedema were managed within lymphoedema services rather than being undiagnosed or misdiagnosed.

Minimising risk

Research related to breast cancer suggests that there are three areas that can potentially help to minimise the risk of lymphoedema onset (BLS, 2023b). Expert opinion is that these principles may be applied to the wider population.

Maintaining a healthy diet and weight

It is really important that patients are aware that a healthy BMI will support reducing the risk of developing any form of lymphoedema as well as supporting other health benefits. However, BMI is not always the best measurement for a patient with lymphoedema and considering waist-hip or waist-height ratio may help in defining obesity levels.

Effective prevention and management of cellulitis

It is important that patients are encouraged to adopt a good skin care regime (ie keeping skin clean and moisturising limbs regularly) to maintain skin integrity. They should also be informed of how to protect the skin from factors that may cause cellulitis.

Exercise and normal use of the limb, including resistance training

Any type of exercise and movement is good for encouraging lymph flow, provided it is increased gradually, including resistance training. Avoidance of activity is likely to lead to more problems and limit range of movement. Advice should be sought from a suitably qualified healthcare professional if guidance is required. If decreased range of movement is present, referral to a musculoskeletal physiotherapist or colleague for assessment and tailored exercises should be considered, as this can improve mobility and support lymph flow.

Compression therapy

Effective prescribing of compression garments requires a comprehensive understanding of garment types, accurate assessment techniques and patient-centred care. Outcomes can be enhanced through correct garment selection, measurement and patient education.

Equally important is advocating for the patient's needs. Working in partnership with them to ensure their preferences, comfort and lifestyle is central to the decision-making process. This can make a tremendous difference in outcomes.

Key challenges in compression therapy

Time pressures and assessment gaps

There is a lack of training in a generalist setting, but support is available. Many garment manufacturers provide free training and advice on the fitting and use of their products. This can help build knowledge and confidence for healthcare professionals in non-specialist settings.

In specialist settings, there may be challenges in accessing prescriptions. This can exacerbate limb conditions, increase cellulitis risk or cause wound recurrence. Accurate, timely assessment is critical to reduce long-term complications and healthcare burden.

Optimising compression for best outcome

Education is vital, as it is important to fit garments and compression wrap systems properly, not just prescribe them, to ensure patients can don and doff.

Improperly fitted garments often result in discomfort, poor compliance and deteriorating limb health. Long-term, this increases clinical workload. Emphasising the importance of proper initial fit can improve patient outcomes and reduce service strain.

Additional resources

- British Lymphology Society: guidelines, educational materials, webinars
- Lymphoedema Support Network
- Manufacturer-specific guides: for measuring, fitting and ordering
- Patient support groups: encouraging shared experiences and compliance.

Advanced interventions

Over the last 20 years, there has been a resurgence in interest in surgery for lymphoedema. Currently, there is limited access to surgery for lymphoedema on the NHS. Most procedures need to be undertaken privately or with special individual funding arrangements.

Application tips

- Use donning aids (eg rubber gloves, frames)
- Align seams correctly
- Avoid twisting or overstretching
- Ensure proper positioning: below-knee garments should sit two fingers below the popliteal crease.

Top tips for looking after garments

- Washing: daily, inside-out, no fabric softener; air-dry only
- Replacement: every 3–6 months, when elasticity diminishes or depending on the guarantee of the garment
- Reassessment: monitor for garment wear or changes in swelling
- Advise patients to own two sets of garments to rotate use while washing and drying.

Conclusions and future directions

Every healthcare professional who encounters someone who has oedema, no matter how mild, should be able to recognise it and start the patient on basic management strategies, without waiting for specialist input. The patient should be referred on, if required, eg if the oedema does not resolve, or if the symptoms are worsening even with first aid treatment.

If there is no lymphoedema service available locally, healthcare providers could collect data on patient outcomes and the impact of unmet need. This includes demonstrating the cost, waste and harm associated with the absence of a dedicated service, highlighting the financial and clinical pressures created by delayed or inadequate care.

Healthcare practitioners may only be individuals but together their voices can make a difference as they will have the trust of the patients as primary care practitioners. Hopefully they can have some of these conversations within healthcare services to raise awareness of the fact that they have nowhere to send these people.

By providing the evidence, collecting data and demonstrating the value and need for lymphoedema services to ensure people are on the most cost-effective pathway, healthcare professionals can show improved patient outcomes and value to the NHS.

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Appendix 1. Myth busters

MYTH: Lymphoedema is rare

REALITY: There are an estimated 450 000 people in the UK receiving treatment for lymphoedema, and there are many more people who have yet to be diagnosed.

MYTH: Breast cancer and its treatment is the main cause of lymphoedema

REALITY: The main causes of lymphoedema are actually obesity and immobility. Cancer treatment can also cause lymphoedema, and can happen anywhere on the body. It is most common in the arms and legs, and some people are born with the condition.

MYTH: People with lymphoedema should not go swimming

REALITY: Swimming is a great activity if you have lymphoedema. Make sure you clean and moisturise your skin afterwards as the chlorine and sea water can be drying, and remember to reapply your sunscreen if needed. You can also wear an old compression garment while swimming.

MYTH: People with lymphoedema need to be careful about exercise

REALITY: Any movement is a fantastic way of boosting lymphatic flow and should be a key part of your supported self-care routine. Build up gradually and keep an eye on your swelling.

MYTH: People with lymphoedema in their arms should not use weights

REALITY: It used to be thought that weight lifting increased swelling, but research now shows that it is a fantastic way of boosting lymphatic flow. When you first start lifting weights, use low weights and low reps and gradually build up your strength.

MYTH: My ankles are swollen but it is not lymphoedema

REALITY: Swelling can happen for a number of reasons and should never be ignored. Whatever the reason, the lymphatic drainage system is not working properly. One of the best ways to help it work better is to be more active. If the swelling lasts for more than 3 months, it becomes a chronic oedema or lymphoedema.

MYTH: You cannot exercise when wearing compression

REALITY: You should keep your compression garment on while you are being active – this helps the muscle pump and boosts lymphatic drainage.

MYTH: My swelling is not bad enough to get treatment

REALITY: Evidence shows the earlier the treatment starts the better the outcome. So it is important not to ignore swelling in the early stages. By getting advice early, you are less likely to experience complications such as cellulitis.

MYTH: People with lymphoedema must not have acupuncture

REALITY: Acupuncture is a supportive and effective therapy that can safely be used by people with or at risk of lymphoedema. While any skin puncture should be avoided in an at risk or affected area, skilled acupuncturists will know how to adapt acupuncture treatment to avoid these areas.

When you see an acupuncturist, tell them you have, or are at risk of, lymphoedema, and ask them to adapt their treatment plan accordingly.

MYTH: My child cannot do PE at school because they have lymphoedema

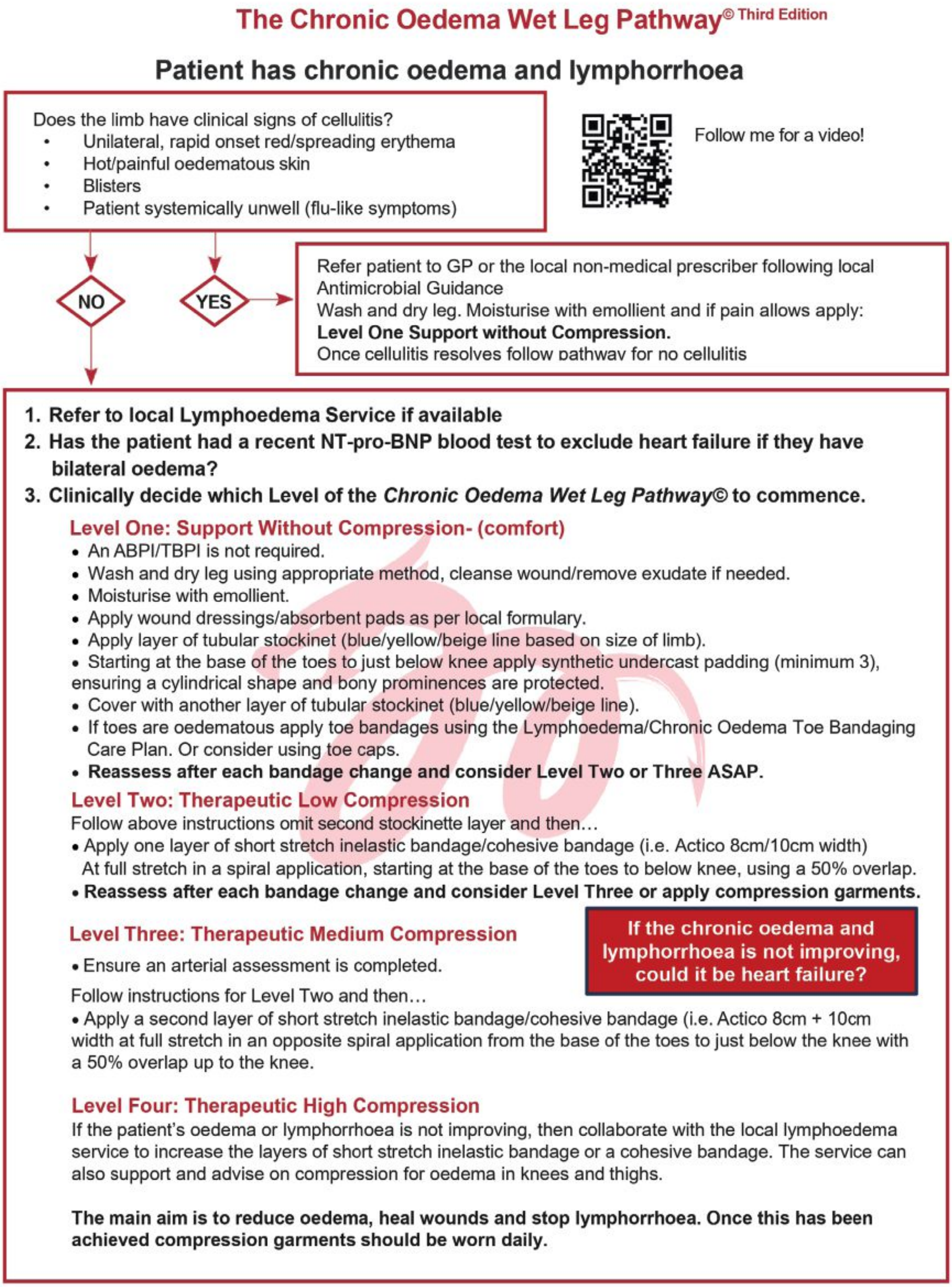
REALITY: Children with lymphoedema should be encouraged to take part in PE, activity is essential for their development, wellbeing and to enhance the benefit of treatment. However the type of exercise may need to be modified in duration or intensity if it causes discomfort or a lasting increase in swelling.

PE teachers should be aware of the importance of prompt treatment of injury to minimise the risk of infection.

MYTH: Compression should not be used in very young children and babies

REALITY: Although babies and young children can be managed without compression, each case is individual and if compression is needed this should be under the guidance of clinicians experienced in treating babies and young children.

Appendix 2: Wet legs pathway and management plan



The Chronic Oedema Wet Leg Pathway© Third Edition

Patient has chronic oedema and lymphorrhoea

Does the limb have clinical signs of cellulitis?

- Unilateral, rapid onset red/spreading erythema
- Hot/painful oedematous skin
- Blisters
- Patient systemically unwell (flu-like symptoms)

Follow me for a video!

Refer patient to GP or the local non-medical prescriber following local Antimicrobial Guidance

Wash and dry leg. Moisturise with emollient and if pain allows apply: **Level One Support without Compression.**

Once cellulitis resolves follow pathway for no cellulitis

1. **Refer to local Lymphoedema Service if available**
2. **Has the patient had a recent NT-pro-BNP blood test to exclude heart failure if they have bilateral oedema?**
3. **Clinically decide which Level of the *Chronic Oedema Wet Leg Pathway©* to commence.**

Level One: Support Without Compression- (comfort)

- An ABPI/TBPI is not required.
- Wash and dry leg using appropriate method, cleanse wound/remove exudate if needed.
- Moisturise with emollient.
- Apply wound dressings/absorbent pads as per local formulary.
- Apply layer of tubular stockinet (blue/yellow/beige line based on size of limb).
- Starting at the base of the toes to just below knee apply synthetic undercast padding (minimum 3), ensuring a cylindrical shape and bony prominences are protected.
- Cover with another layer of tubular stockinet (blue/yellow/beige line).
- If toes are oedematous apply toe bandages using the Lymphoedema/Chronic Oedema Toe Bandaging Care Plan. Or consider using toe caps.
- **Reassess after each bandage change and consider Level Two or Three ASAP.**

Level Two: Therapeutic Low Compression

Follow above instructions omit second stockinette layer and then…

- Apply one layer of short stretch inelastic bandage/cohesive bandage (i.e. Actico 8cm/10cm width) At full stretch in a spiral application, starting at the base of the toes to below knee, using a 50% overlap.
- **Reassess after each bandage change and consider Level Three or apply compression garments.**

Level Three: Therapeutic Medium Compression

- Ensure an arterial assessment is completed.

Follow instructions for Level Two and then…

- Apply a second layer of short stretch inelastic bandage/cohesive bandage (i.e. Actico 8cm + 10cm width at full stretch in an opposite spiral application from the base of the toes to just below the knee with a 50% overlap up to the knee.

If the chronic oedema and lymphorrhoea is not improving, could it be heart failure?

Level Four: Therapeutic High Compression

If the patient's oedema or lymphorrhoea is not improving, then collaborate with the local lymphoedema service to increase the layers of short stretch inelastic bandage or a cohesive bandage. The service can also support and advise on compression for oedema in knees and thighs.

The main aim is to reduce oedema, heal wounds and stop lymphorrhoea. Once this has been achieved compression garments should be worn daily.

Chronic Oedema Wet Leg Management Plan©

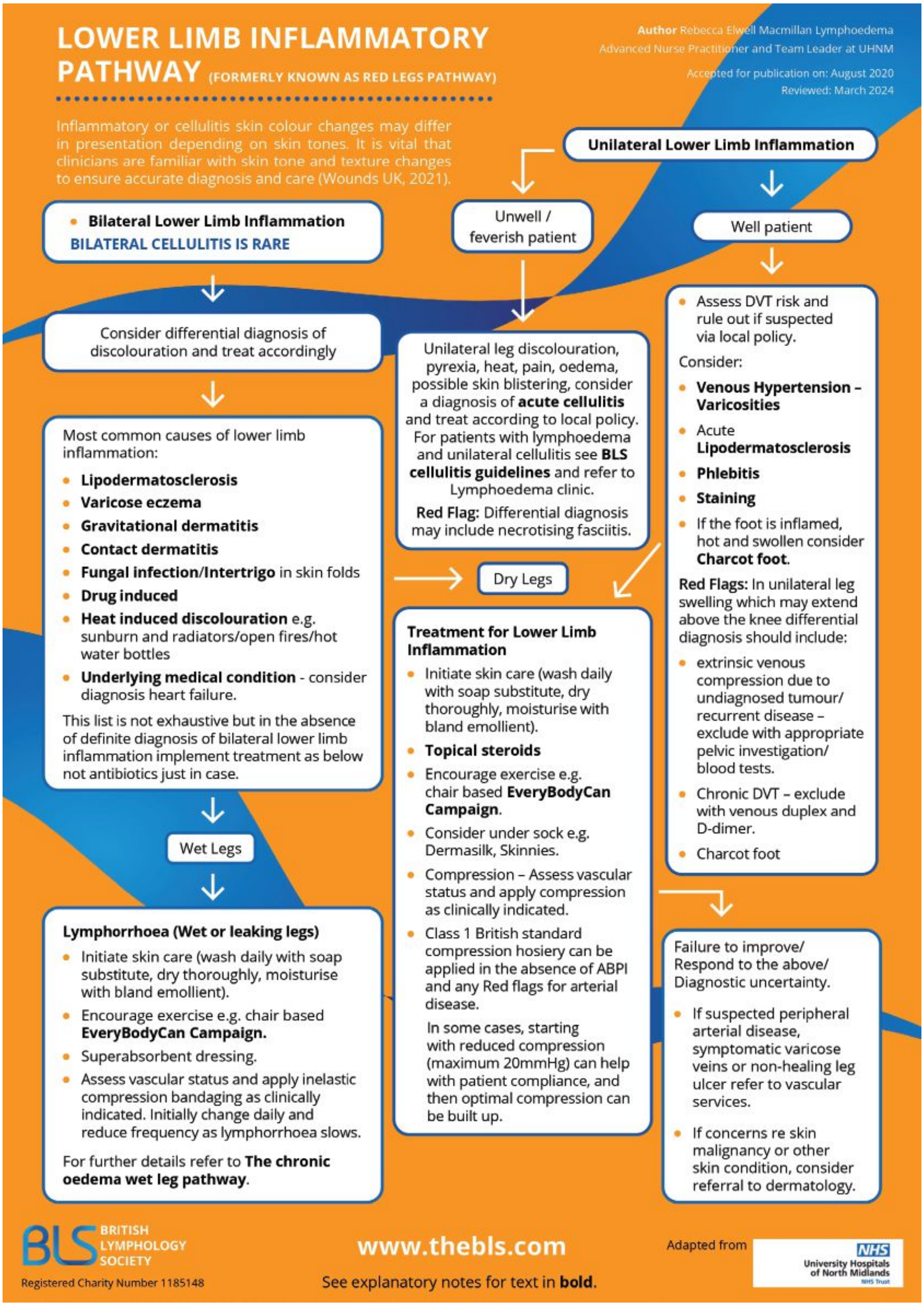
PATIENT NAME:	**DATE OF BIRTH:**	**THERAPIST NAME:**	**DATE:**

Has patient had a recent NT Pro BNP to exclude heart failure? YES ☐ NO ☐ Requested from GP? YES ☐ NO ☐

Level	Products Required	Instructions
Level One Support without Compression **An ABPI/TBPI is not required**	• Two pieces of Blue/Yellow/ Beige tubular stockinet • Minimum of 3 rolls of synthetic undercast padding • Wound dressing (if appropriate)	• Wash and dry leg and cleanse wound/remove exudate if needed. • Moisturise with emollient. • Apply wound dressings/ absorbent pads as per local wound formulary. • Apply layer of tubular stockinet (Blue/Yellow/Beige line based on size of limb). • Starting at the base of the toes to just below knee apply synthetic undercast padding ensuring a cylindrical shape is achieved and bony prominences are covered and protected. • Cover with a final layer of tubular stockinet (Blue/Yellow/Beige line). • If toes are oedematous apply toe bandages using the Lymphoedema/Chronic Oedema Toe Bandaging Care Plan. Or consider using toe caps. **Reassess at each bandage change and consider Level Two or Three ASAP**
Level Two Therapeutic Low Compression **An ABPI/TBPI is not required**	As above and add • Short stretch inelastic bandage/ cohesive (8cm x 1 roll + 1/2 rolls of 10cm width)	Follow above instructions but omit second layer of stockinette and then… • Apply **one** layer of short stretch inelastic bandage or a cohesive bandage (i.e. Actico 8cm or 10cm width around calf stretched fully in a spiral application, starting at the base of the toes to below knee using a 50% overlap. **Reassess at each bandage change and consider Level Three or Level Four or apply compression garments.**
Level Three Therapeutic Medium Compression **Arterial assessment is required**	As above and add • Short stretch inelastic/cohesive bandage (10cm width)	Follow instructions for Level Two and then… • Apply a second layer of short stretch inelastic bandage or a cohesive bandage (i.e. Actico 10cm width) at full stretch in an opposite spiral application from the base of the toes to just below the knee with a 50% overlap **Reassess, consider Level Four or apply compression garments. If not improving, consider NT-pro-BNP blood test to exclude heart failure**
Level Four Therapeutic High Compression **Collaboration with Lymphedema Services**	As above and add • Short stretch inelastic/ cohesive bandage (10cm width)	If the patient's oedema or lymphorrhoea is not improving, then collaborate with the local lymphoedema service to increase the number of layers of short stretch inelastic bandage or a cohesive bandage. The service can also support and advise on compression for oedema in knees and thighs. **The main aim is to reduce oedema, heal wounds and stop lymphorrhoea once this has been achieved compression garments should be worn daily.**

Watch the LWCN Chronic Oedema Wet Leg Video:

Appendix 3: Lower limb inflammatory pathway



LOWER LIMB INFLAMMATORY PATHWAY (FORMERLY KNOWN AS RED LEGS PATHWAY)

Author Rebecca Elwell Macmillan Lymphoedema Advanced Nurse Practitioner and Team Leader at UHNM

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Inflammatory or cellulitis skin colour changes may differ in presentation depending on skin tones. It is vital that clinicians are familiar with skin tone and texture changes to ensure accurate diagnosis and care (Wounds UK, 2021).

- **Bilateral Lower Limb Inflammation**

BILATERAL CELLULITIS IS RARE

Consider differential diagnosis of discolouration and treat accordingly

Most common causes of lower limb inflammation:

- **Lipodermatosclerosis**
- **Varicose eczema**
- **Gravitational dermatitis**
- **Contact dermatitis**
- **Fungal infection/Intertrigo** in skin folds
- **Drug induced**
- **Heat induced discolouration** e.g. sunburn and radiators/open fires/hot water bottles
- **Underlying medical condition** - consider diagnosis heart failure.

This list is not exhaustive but in the absence of definite diagnosis of bilateral lower limb inflammation implement treatment as below not antibiotics just in case.

Wet Legs

Lymphorrhoea (Wet or leaking legs)

- Initiate skin care (wash daily with soap substitute, dry thoroughly, moisturise with bland emollient).
- Encourage exercise e.g. chair based **EveryBodyCan Campaign.**
- Superabsorbent dressing.
- Assess vascular status and apply inelastic compression bandaging as clinically indicated. Initially change daily and reduce frequency as lymphorrhoea slows.

For further details refer to **The chronic oedema wet leg pathway**.

Dry Legs

Treatment for Lower Limb Inflammation

- Initiate skin care (wash daily with soap substitute, dry thoroughly, moisturise with bland emollient).
- **Topical steroids**
- Encourage exercise e.g. chair based **EveryBodyCan Campaign**.
- Consider under sock e.g. Dermasilk, Skinnies.
- Compression – Assess vascular status and apply compression as clinically indicated.
- Class 1 British standard compression hosiery can be applied in the absence of ABPI and any Red flags for arterial disease.

In some cases, starting with reduced compression (maximum 20mmHg) can help with patient compliance, and then optimal compression can be built up.

Unilateral Lower Limb Inflammation

Unwell / feverish patient

Unilateral leg discolouration, pyrexia, heat, pain, oedema, possible skin blistering, consider a diagnosis of **acute cellulitis** and treat according to local policy. For patients with lymphoedema and unilateral cellulitis see **BLS cellulitis guidelines** and refer to Lymphoedema clinic.

Red Flag: Differential diagnosis may include necrotising fasciitis.

Well patient

- Assess DVT risk and rule out if suspected via local policy.

Consider:

- **Venous Hypertension – Varicosities**
- Acute **Lipodermatosclerosis**
- **Phlebitis**
- **Staining**
- If the foot is inflamed, hot and swollen consider **Charcot foot**.

Red Flags: In unilateral leg swelling which may extend above the knee differential diagnosis should include:

- extrinsic venous compression due to undiagnosed tumour/ recurrent disease – exclude with appropriate pelvic investigation/ blood tests.
- Chronic DVT – exclude with venous duplex and D-dimer.
- Charcot foot

Failure to improve/ Respond to the above/ Diagnostic uncertainty.

- If suspected peripheral arterial disease, symptomatic varicose veins or non-healing leg ulcer refer to vascular services.
- If concerns re skin malignancy or other skin condition, consider referral to dermatology.

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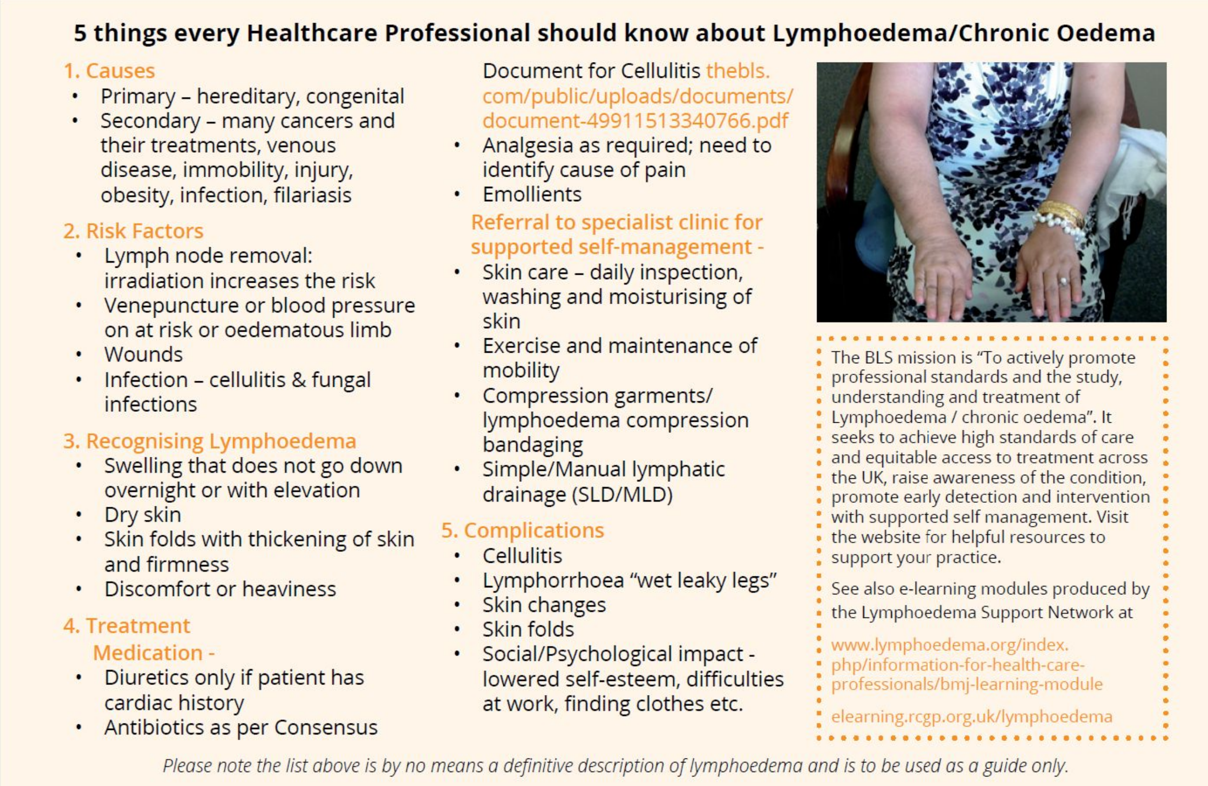
See explanatory notes for text in **bold**.

Adapted from NHS University Hospitals of North Midlands NHS Trust

Appendix 4. Information for all healthcare professionals



5 things every Healthcare Professional should know about Lymphoedema/Chronic Oedema

1. Causes
- Primary – hereditary, congenital
- Secondary – many cancers and their treatments, venous disease, immobility, injury, obesity, infection, filariasis

2. Risk Factors
- Lymph node removal: irradiation increases the risk
- Venepuncture or blood pressure on at risk or oedematous limb
- Wounds
- Infection – cellulitis & fungal infections

3. Recognising Lymphoedema
- Swelling that does not go down overnight or with elevation
- Dry skin
- Skin folds with thickening of skin and firmness
- Discomfort or heaviness

4. Treatment

Medication -
- Diuretics only if patient has cardiac history
- Antibiotics as per Consensus Document for Cellulitis thebls.com/public/uploads/documents/document-49911513340766.pdf
- Analgesia as required; need to identify cause of pain
- Emollients

Referral to specialist clinic for supported self-management -
- Skin care – daily inspection, washing and moisturising of skin
- Exercise and maintenance of mobility
- Compression garments/lymphoedema compression bandaging
- Simple/Manual lymphatic drainage (SLD/MLD)

5. Complications
- Cellulitis
- Lymphorrhoea "wet leaky legs"
- Skin changes
- Skin folds
- Social/Psychological impact - lowered self-esteem, difficulties at work, finding clothes etc.

The BLS mission is "To actively promote professional standards and the study, understanding and treatment of Lymphoedema / chronic oedema". It seeks to achieve high standards of care and equitable access to treatment across the UK, raise awareness of the condition, promote early detection and intervention with supported self management. Visit the website for helpful resources to support your practice.

See also e-learning modules produced by the Lymphoedema Support Network at

www.lymphoedema.org/index.php/information-for-health-care-professionals/bmj-learning-module

elearning.rcgp.org.uk/lymphoedema

Please note the list above is by no means a definitive description of lymphoedema and is to be used as a guide only.

Appendix 5. Guidelines on management of cellulitis and lymphoedema

Information on differential diagnoses, red flags, antibiotic pathways and a management plan.

https://sbuhb.nhs.wales/go/discharge-support/pathways-and-services/lymphoedema-service/lymphoedema-service-folder/cellulitis-pathway-final-v50-20032022pdf/

Appendix 6. Making sure the shoe fits

Footwear is key in keeping people mobile. It is important to recommend adequately fitting footwear to accommodate the oedema in the feet and ankles, while ensuring the right support and that walking is comfortable.

Because of the variation in shoe shape, brand, materials and the fact that many manufacturers use their own sizing standards that do not always adhere to international standards, giving simple, key advice to your patient is important.

Some basic advice that you might consider giving to your patient when they are choosing shoes can be found in the NHS Wales lymphoedema and footwear document: https://lwcn.nhs.wales/files/ip9054-k-footwear-booklet-v2-0-pdf/

Lymphoedema is everyone's business

Appendix 7. Advice for patients: get moving with lymphoedema

Keeping active has specific benefits for the lymphatic system. Working muscles and deeper breathing caused by extra effort of activity increases the flow of lymph, preventing or reducing swelling and helping the body to rid itself of harmful substances, such as bacteria.

Managing lymphoedema can be a challenge. Being active not only helps reduce lymphatic swelling and prevent other complications; it helps individuals stay in control rather than allowing lymphoedema to control their daily lives.

On top of that, regular activity strengthens muscles, keeps joints flexible, maintaining and improving range of movement, improving posture, body shape, confidence and independence.

Where can I exercise?

Many leisure centres offer free temporary and reduced fee memberships with professional trainer guidance and support. Ask your GP, lymphoedema practitioner or local leisure centre about this. There are also many local voluntary groups and websites that might give you some ideas, motivation and support in getting more active. Being active does not necessarily mean hitting the gym though. You can also keep yourself active and healthy by doing more of 'everyday' activities in the home or garden and being more aware of avoiding long periods of sitting still. Take every opportunity to move and stretch. There are lots of tips on thebls.com.

Extreme or contact sports

If your chosen activity has a high risk of injury to the skin, such as contact sports, you may need to take some precautions to reduce the likelihood of injury. Make sure you always clean any wounds and have a supply of prophylactic antibiotics in case an infection occurs.

Tip on getting started

- It is important to build up any activity gradually. Too much activity, for too long, progressed too quickly may increase swelling. If that happens, reduce the amount or intensity of activity until it goes down, then start building up again.
- The right amount of activity is different for everyone so monitor any effect of activity on swelling by regularly checking the affected area. Even if you are very active, intense activity may increase swelling temporarily, but as long as it goes back down within 24 hours, there is no need to cut back on activity.
- A few people find a particular activity may worsen any swelling. This does not mean that you cannot active – just experiment with a different type of activity.
- It is normal to become slightly out of breath when you are challenging your body to be more active than usual. However, if it becomes unreasonably uncomfortable, take a rest before doing more. If it persists, seek advice from your specialist practitioner or GP.

Don't forget

- If you have been prescribed a compression garment, always wear these when being active and make sure these are a good fit. Breath deeply to encourage better circulation of blood and lymph.
- Build up gradually. If you notice swelling becomes worse, stop the activity until the swelling goes back down. You can restart, but take it a bit slower and easier.
- Whatever your activity, do it regularly. If you are unable to do it for a long period, when you restart, do so slowly and gradually.
- Make sure to not exert yourself or exercise for too long. Short, regular periods of activity with rests in between are better than long periods of activity, especially if you are not used to it. Alternatively, try something different – varying the activity is better than doing the same movements repeatedly, so that different muscles are worked and rested.

Scan the QR code for more details

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