

**SMASAC Short Life Working Group on  
Lymphoedema**

# **Lymphoedema Care in Scotland**

**Achieving Equity and Quality**

Produced in Partnership between the Scottish Government and  
Macmillan Cancer Support

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## Definition and Vision

### What is lymphoedema?

Lymphoedema is a chronic, progressive condition resulting from failure of the lymphatic system to drain fluid from tissue spaces throughout the body and return it to the circulatory system. The two main types of lymphoedema are:

- Primary lymphoedema, which may be present at birth and develop at puberty or in mid-life because of abnormal development of the lymphatic system.
- Secondary lymphoedema, which arises when lymphatic failure results from damage to an otherwise normal lymphatic system.

The result is swelling that most commonly affects the limbs. However, lymphoedema can affect the chest, back, abdomen, buttocks, breast or genitalia in isolation or in combinations with limb oedema. It is important to note that swelling can occur for different reasons, including cancer, cancer treatment, trauma, vascular causes or congenital causes. Secondary problems of pain, infection, mobility limitations and reduced quality of life are common. (British Lymphology Society 2013)

### What is the vision for lymphoedema care in Scotland?

This report supports the “Vision Statement” for lymphoedema care in Scotland developed by participants at the May 2013 “Spring Soiree” and endorsed by the Macmillan Lymphoedema Project for Scotland and the Health and Social Care Alliance Scotland (the ALLIANCE):

“Our vision is one in which people are

Getting the **DETAILS** right!

Prompt **D**agnosis, **E**ducation and **T**reatment with **A**ccess to Information on Lymphoedema and **S**upporting individuals’ emotional and physical needs.”

## Introduction

Lymphoedema is a serious long-term condition, often under-recognised and under-reported by the NHS in Scotland. There are thought to be approximately 20,000 people living with lymphoedema in Scotland. In this Scottish Medical and Scientific Advisory Committee (SMASAC) report we provide information on the nature and extent of the problem, diagnosis and management (including supported self management). We go on to make a number of recommendations for SGHSCD, territorial Health Boards, NHS Education Scotland and Healthcare Improvement Scotland which we believe will help improve both equity and quality of care for patients with this condition. We have focused on using whatever evidence is available and highlight areas where further research is needed.

The overall approach we suggest is that of coordinated, equitable and accessible services across Scotland supported by developing education and training of appropriate skills and knowledge for health professionals who may deal with lymphoedema whether that is in general practice, the community or more specialised settings. Access to a specialised surgical opinion for a small proportion of patients most severely affected is an important recommendation.

We highlight the problems of obesity and immobility which can contribute to deterioration; to address these we suggest ideas for supported self management as well as other modalities of treatment for patients. Timely advice and education could have a significant role in reducing the incidence and severity of lymphoedema. We believe that such anticipatory and preventive approaches could make a substantial difference to the quality of life of many patients with this under-recognised and complex condition. Our recommendations should be seen in the context of the forthcoming integration of health and social care in Scotland, set out in the Public Bodies (Joint Working) Bill 2013.

This report builds on several previous strands of work.

A Scottish Medical Advisor's Scientific Advisory Group (SMASAC) developed a draft pathway for lymphoedema care in 2009. Work undertaken by Breakthrough Breast Cancer made an initial set of management recommendations in 2011. Macmillan Cancer Support has developed further recommendations through work hosted by the Health and Social Care Alliance for Scotland (ALLIANCE). The need for national recommendations on the treatment of people with or at risk of lymphoedema was recognised in 2012 by the CMO, Sir Harry Burns.

In June 2012 SMASAC therefore convened this Short Life Working Group on Lymphoedema with a view to producing these recommendations. Members (Appendix 1) were co-opted from SMASAC (specialist clinical representatives), the Macmillan Lymphoedema Project (Project Manager), the University of Glasgow, and

the Scottish Lymphoedema Practitioners Network. We have also sought the views of patients with lymphoedema, and this is reflected in our findings and recommendations. The inaugural meeting of the Working Group was held in September 2012 with a view to presenting final recommendations to SMASAC in September 2013.

Initial work by the University of Glasgow and the Macmillan Lymphoedema Project (Sneddon et al 2008) identified inequity of service provision across Scotland, especially for patients with a diagnosis other than breast cancer. Some services are poorly resourced and there is evidence that many clinicians have significant learning needs. Lack of recognition of the condition and its treatment may impact on clinical management and mean opportunities to prevent complications are missed. Some patients have substantial distress and unmet physical and psychological support needs.

Due to the similarity of the ambitions of both the SMASAC Short Life Working Group and the Macmillan Lymphoedema Project for Scotland we felt that the *joint* production of national recommendations would use the strengths of both approaches, involving specialists, general practitioners and nurses, lymphoedema professionals and patients, and this is reflected in this report. We propose a model which is a comprehensive NHS Scotland Lymphoedema Service based on a tiered approach.

I am very grateful to all members of the group for their substantial contributions to the report and the commitment and energy that they have shown over the past year. I believe that in the NHS in Scotland, we now have a firm basis for improving both equity and quality of care for patients with lymphoedema.

A handwritten signature in black ink, appearing to read 'John Gillies', with a stylized flourish at the end.

Dr John Gillies

Chair

## Executive Summary

- Lymphoedema is a common and under-recognised condition, affecting up to 21,000 people in Scotland.
- Those at risk include patients with a family history of lymphoedema, cancer, inflammatory joint disease, burns, chronic oedema, immobility and recurrent cellulitis.
- Early recognition and initiation of treatment can prevent complications in those at risk.
- Primary care needs to be supported as the main burden of care falls on primary care to support the patients to manage the condition and its complications, and to signpost patients to relevant materials.
- The priorities identified by lymphoedema patients are: receiving the best treatment for lymphoedema care; a prompt diagnosis; being able to access treatment quickly; rapid treatment of cellulitis; prompt replacement of hosiery; GP/lymphoedema care provider being aware of the condition; access to care locally; and being supported to self-manage.
- Management consists of skin care, physical therapy to maximize lymph flow and venous return, compression therapy and psychosocial support. Surgery is necessary for a small number of severe cases.
- Supported self management is an essential part of modern treatment of lymphoedema.
- There is currently a wide variation in the organisation and delivery of lymphoedema services across Health Boards.
- A comprehensive NHS Scotland Lymphoedema Service, based on a tiered approach is suggested.
- Improved education and training for all health professionals involved in lymphoedema care is necessary.
- Further recommendations include improved coding, development of QPIs, a SIGN guideline for lymphoedema and suggestions for research funding streams.

## Section 1 – The Size and Nature of the Problem

Studies of the prevalence of lymphoedema in the UK have suggested that between 1.33 and 3.99 in 1,000 people of all ages are affected by lymphoedema, with increasing prevalence in people over the age of 65 (Moffatt et al, 2003; Moffatt and Pinnington, 2012). The incidence of primary lymphoedema is approximately 1 in 6,000 births (Dale, 1985). We can therefore estimate that between 7,000 and 21,000 people are affected by secondary lymphoedema and approximately 10 children are born each year with primary lymphoedema in Scotland. The wide range reflects the relative lack of good data and these figures are likely to be an underestimate. The prevalence of lymphoedema in breast cancer patients has been reported as between 12% and 60% (Mortimer et al, 1996; Schrenk et al, 2000; Meric et al, 2002; Ozaslan and Kuru, 2004) and in patients treated for gynaecological cancers as between 28% and 47% (Hong et al, 2002; Ryan et al, 2003).

Lymphoedema, particularly if not well controlled, carries significant human, personal, financial and societal costs. Pain associated with lymphoedema is underestimated: one study identified it as a significant problem for 50% of people with lymphoedema (Moffatt et al, 2003). The same study identified that 29% of patients experienced cellulitis and required hospitalisation for systemic antibiotics. Inadequate treatment increases risk of complications including fibrosis, papillomatosis (the development of warty growths on the skin consisting of dilated lymphatics and fibrous tissue) and lymphorrhoea (leakage of lymph fluid through the skin), in addition to increasing swelling, immobility and functional limitations (Sneddon et al, 2008). There may be significant psychological morbidity, social isolation and limitation of life choices, including employment opportunities (Moffatt et al, 2003; Sneddon et al, 2008). The morbidity associated with poorly treated lymphoedema not only decreases the quality of life (Morgan et al, 2005), but also increases dependence on health and social services and costs of care provision. Conversely, accurate early diagnosis and control of the physical impact of lymphoedema at an early stage can reduce the social and psychological impact of the condition.

The burden and costs associated with lymphoedema care have the potential to increase significantly in the next decade as the prevalence of lymphoedema is likely to rise in tandem with expected increases in at-risk groups, including older people who are less mobile, those who are obese and some cancer patients.

Estimating the number of people affected by lymphoedema in Scotland is difficult. Hospital coding of lymphoedema is known to be incomplete and coding by GP practices is not systematic. Under-recognition and under-treatment of lymphoedema also mean that data from healthcare systems are likely to underestimate the true prevalence and burden of disease.

Appendix 2 shows more data on health service provision for lymphoedema in Scotland.

## Recommendation

1	<p>Health Boards should accurately identify the extent of lymphoedema through improved coding.</p> <p>On confirmation of diagnosis the following READ codes are recommended:</p> <ul style="list-style-type: none"><li>• G860.- lymphoedema post mastectomy</li><li>• G861.- other lymphoedema.</li></ul> <p>ICD10 codes for lymphoedema: I89.0, I97.2, Q82.0 in any diagnosis position.</p>
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## Section 2 – Diagnosis and Management

### 2.1 Recognition of at-risk populations

Early identification and initiation of treatment is vital in lymphoedema to prevent complications and give the best possible outcomes for the patient. Early intervention has been shown to minimize the severity of lymphoedema, reduce the frequency of complications and lessen the need for complex treatment (Norman et al, 2009; Lund et al, 2011). Yet a study in Scotland highlighted that patients with lymphoedema found that their symptoms had not always been taken seriously or dealt with sensitively by health care professionals and that many experienced long delays in diagnosis and accessing appropriate treatment (Sneddon et al, 2008). A later study highlighted a perceived need across all professional groups for education in relation to recognition of early lymphoedema, selection of appropriate treatment and awareness of available referral pathways (Davies et al, 2012).

It should be recognised that a wide range of clinicians come into contact regularly with and manage issues related to lymphoedema. Therefore, clinicians managing conditions that either cause or co-exist with lymphoedema also require generalist skills to reduce the risk of lymphoedema, prevent lymphoedema from getting worse, and treat complications such as infections (cellulitis) early and vigorously.

It is possible to identify certain groups of individuals in the population who are more likely to develop lymphoedema. In particular, those with a family history of lymphoedema and those who have been treated for cancers in which the treatment has compromised regional lymph nodes are known to be at risk. It is also known that the incidence of lymphoedema increases with age (Moffatt et al, 2003; Moffatt et al, 2012; Sneddon et al, 2008) and obesity (Soran et al, 2011). The elderly population has an increased risk of lymphoedema, largely as a consequence of co-morbidities and mobility limitations. Additionally, increased risk is associated with the following conditions:

- Cancer: particularly of breast, reproductive organs, bladder, head and neck, melanoma
- Inflammatory joint disease
- Extensive burns, scarring or trauma involving lymph nodes
- Venous problems and poor venous return that overload the lymphatic system, e.g. venous hypertension, chronic oedema
- Chronic skin problems, e.g. psoriasis, eczema
- Family history of lymphoedema or 'heavy legs', which may reflect undiagnosed lymphoedema
- Severe mobility problems
- Recurrent cellulitis (Keeley, 2008).

In those 'at risk' or those with lymphoedema, the following factors may further increase the risk of developing or exacerbating lymphoedema:

- In cancer patients: lymph node excision; radiation to lymph node field; delayed wound healing
- In those treated for breast cancer: history of axillary web syndrome (cording); seroma; exercise above shoulder height within seven days of breast surgery; weight gain following treatment
- Other co-morbidities, e.g. diabetes, multiple sclerosis
- Immobility
- Recurrent cellulitis
- Trauma to the skin
- Wound healing problems
- Insect bites
- Sunburn
- Fungal infections, especially between toes
- Poor hygiene.

Venesection is frequently listed as a risk factor, as is the taking of blood pressure, in the arm of a person treated for breast cancer, on the affected side. Although anecdotal evidence exists, there is currently no research evidence to support this. However, to err on the side of caution, patients and health professionals are encouraged to use the arm on the unaffected side where possible.

Given the trend towards an increasingly elderly and obese population, it is important that health and social care professionals are aware of lymphoedema, who is at risk and what preventative strategies can be employed. Lack of awareness in health care professionals may result in missed opportunities to promote self care and risk reduction to minimise the severity and impact of the condition.

## 2.2 Interventions for minimising risk

### Targeted screening, monitoring and prevention programmes in cancer-related lymphoedemas

There is emerging evidence that targeted screening, monitoring and preventative strategies have the potential to reduce the risk of developing chronic lymphoedema (Stout Gergich et al, 2008). Small uncontrolled studies of prevention programmes involving patients with breast, gynaecological and urological cancers have supported these findings (Lund et al, 2011; Mew and Kirwan, 2010; Box et al, 2002; Hayes et al, 2008).

## General health promotion advice

Maintaining a healthy diet and weight, being physically active, not smoking, and reducing alcohol intake will help to minimise the risk of lymphoedema.

## Specific preventative strategies

Key strategies for prevention are maintaining the integrity of the skin, preventing injury or infection and enhancing lymphatic system functioning through physical activity and breathing exercises. Prevention and early, vigorous treatment of cellulitis, to which individuals with lymphatic insufficiency are vulnerable, is important, as described in the British Lymphology Society/Lymphoedema Support Network Consensus Guidelines (2010), available from:

[http://www.thebls.co.uk/patients/files/consensus\\_on\\_cellulitis\\_aug\\_10.pdf](http://www.thebls.co.uk/patients/files/consensus_on_cellulitis_aug_10.pdf)

## Genetic counselling for inherited lymphoedema

A proportion of the small number of people with primary lymphoedema will have a genetic predisposition. There is scope for reducing future incidence through genetic counselling.

## 2.3 Diagnosis

The diagnosis of lymphoedema is based upon clinical history, physical examination and confirmation of the diagnosis by specific tests. Lymphoedema can often be diagnosed by its characteristic clinical presentation, yet, in some cases, ancillary tests might be necessary to establish the diagnosis, particularly in the early stages of the disease and in oedemas of mixed aetiology. Identification of other causes of oedema may not preclude a co-existing lymphoedema. People with a degree of lymphoedema often have a number of co-morbidities which may make its identification challenging. Appendix 3 provides examples of such cases, with details of how diagnosis was determined and suggested management options.

The typical clinical history of primary lymphoedema includes:

- Possible family history of lymphoedema or 'thick legs'
- Swelling of part of body from birth or in early years
- More common in females, often arising around menarche, pregnancy or menopause
- No identifiable cause of swelling, other conditions having been excluded
- Acute cellulitis – may be a consequence of previously undiagnosed lymphoedema or it may precipitate lymphoedema in someone with latent lymphoedema.

The typical clinical history of secondary lymphoedema includes:

- History of condition known to compromise lymphatic system
- May be triggered by:
  - Uncharacteristic physical activity
  - Immobility
  - Minor or major trauma to 'at risk' part of body
  - Recurrent infections
  - Acute or chronic inflammatory process.

Early signs and symptoms may include:

- Swelling, usually of a limb, but not always
- Swelling is soft and oedematous initially
- Feelings of tightness, discomfort, tension, heaviness, tightness of jewellery (in limb).

Later signs and symptoms may include:

- Swelling that does not resolve overnight or on elevation
- Dry, scaly skin, skin becoming thickened and horny over time (hyperkeratosis), with possible lymph blisters or papillomatosis
- Thickening of tissues, becoming firmer over time with evidence of fibrotic changes
- Deepened skin folds and distortion of limb shape, squaring of toes
- Stemmer's Sign: inability to pick up a fold of skin at the base of the second digit in an affected limb
- Weeping from skin, 'wet legs' (lymphorrhoea).

## Investigations

In suspected primary lymphoedema, specialist investigations may be required to confirm diagnosis, differentiate it from lipoedema and determine which parts of the lymphatic system are improperly developed. Such investigations may include lymphoscintigraphy, magnetic resonance imaging, ultrasonography or CT.

In suspected secondary lymphoedema differential diagnosis may be aided by:

- Examination of the cardiovascular system to exclude heart failure. Other causes of leg swelling include low protein states caused by a variety of conditions including liver disease, nephrotic syndrome and severe malnutrition. Simple blood tests will measure liver and renal function and serum proteins.

- Drug therapies, for example some of the calcium channel blockers, Steroids, Taxanes may cause localised leg and especially ankle swelling due to local capillary dilatation; thus, a careful drug history must be obtained.
- Individuals who are significantly obese (BMI >35) may have swollen legs due to dependent oedema.
- Recurrent disease for example cancer and lymphadenopathy.

## 2.4 Treatment

The aims of treatment for lymphoedema are to:

- Maximise the efficiency of the functioning lymphatics to enable
  - Reduction of swelling and maintenance of reduction
  - Improved condition of skin and subcutaneous tissue and limb shape
- Prevent or reduce exacerbations and complications such as cellulitis
- Maximise the individual's ability to self-manage the condition once a treatment regime with which the patient is comfortable and competent is in place and the condition is stable
- Improve quality of life
- For secondary lymphoedema, identify causes of reversible lymphoedema (for example, heart failure, obesity and immobility) and actively manage the underlying condition.
- Management strategies for all patients will involve a lifelong daily regime of care, including:
  - Skin care to preserve integrity and prevent trauma or infection
  - Physical activity/movement/positioning to maximise lymphatic flow and venous return
  - Compression therapy, the nature of which is determined by severity and other patient related factors
  - Potentially, lymphatic drainage and other specialist interventions determined by severity and other patient-related factors such as manual lymphatic drainage
  - Supported self care
  - Decongestives being recommended for regular use.

## Self management

Self management is the development of skills a person uses to manage their medical condition. These skills can enable people to come to terms with lymphoedema, stay well-informed, and become confident and capable of undertaking some, if not all, of their treatment. Self management is not a replacement for formal health care but allows people to take as much control as they feel able to, supported by health and

social care professionals. It replaces the paternalistic approaches of the past and provides an element of control to the individual.

The ability to self manage differs from one person to another. Therefore, self management should be individual to each person's ability. It must be recognised that the ability to self manage can fluctuate due to changes in circumstance and/or deterioration of the condition and therefore reliance on professional support may change over time.

In October 2012, the Macmillan Lymphoedema Project for Scotland produced "Top Tips for the Self Management of Lymphoedema – A Guide" with input from people with lymphoedema. The resource, which is aimed at people living with lymphoedema, their carers, and care professionals, is available via the Macmillan Cancer Support <http://www.macmillan.org.uk/Home.aspx> and NHS Inform websites <http://www.nhsinform.co.uk/>. The guide covers the recognition of signs and early symptoms of lymphoedema, understanding feelings, skin care, avoiding infection, staying active, breathing, lymphatic drainage, limb positioning and movement, diet and lifestyle.

The main burden of care falls on primary care to support the patients to manage the condition and its complications, and to signpost patients to relevant materials. More information is available at appendix 5.

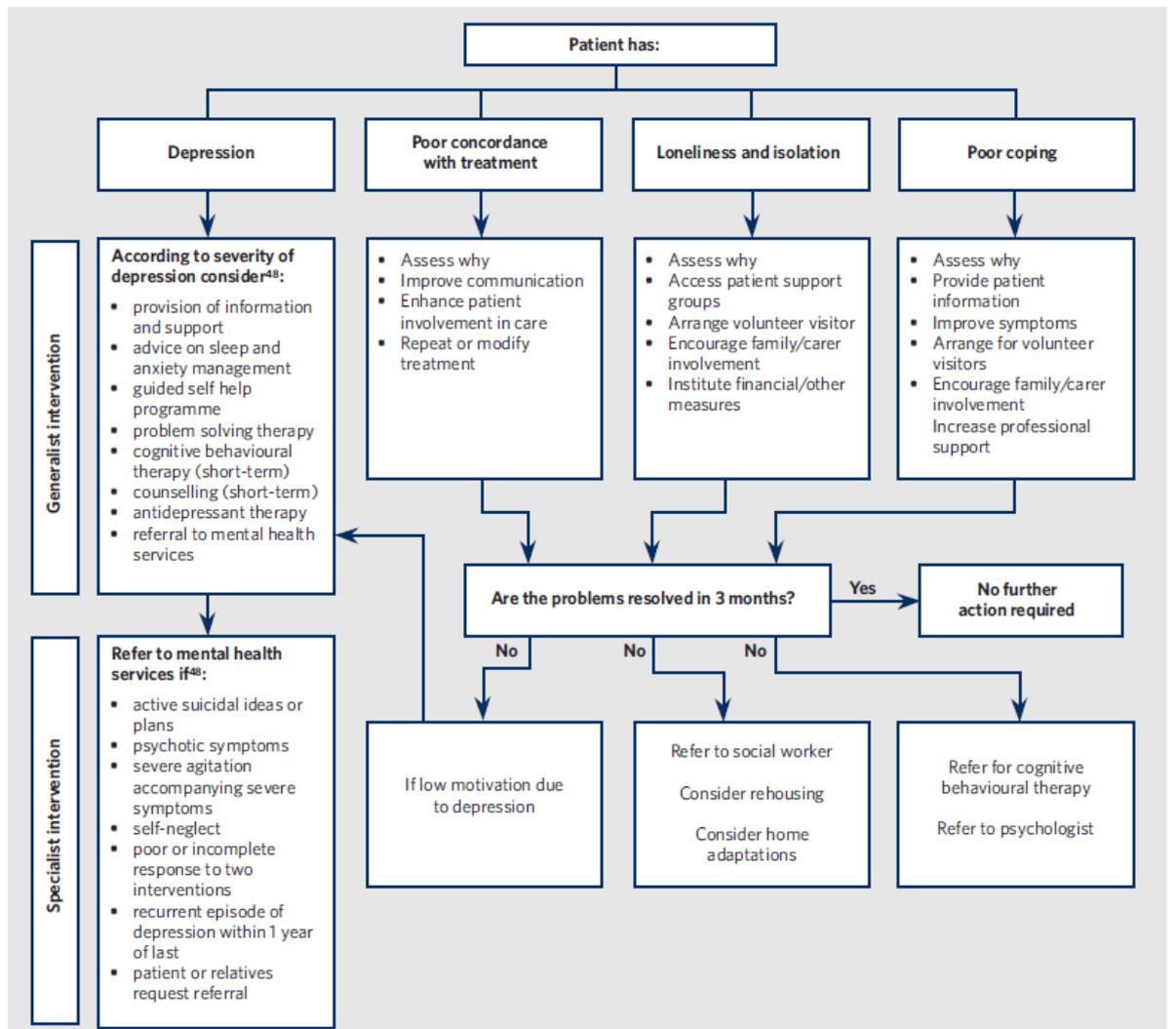
Additional sources of information and guidance on self management for both patients and professionals can be found in Appendix 6.

### Psychosocial support

Psychosocial support is an important element of the holistic treatment of lymphoedema: it has the potential to have considerable influence on outcome by enhancing concordance, encouraging self management and maximising quality of life. Intervention involves planning and implementing psychosocial care strategies that help patients and their family/carers to take a positive role in the management of their lymphoedema and to achieve as good a quality of life as possible.

If psychosocial problems are not resolved within three months, the patient should be referred for specialist psychology assessment. The algorithm below (Figure 1) outlines the process.

Figure 1. Algorithm for psychosocial support, assessment and referral.  
(Lymphoedema Framework. *Best Practice for the Management of Lymphoedema. International consensus*. London: MEP Ltd, 2006.)



## Surgery

Surgical treatment of lymphoedema can be divided into three main categories:

- Surgical reduction
- Procedures that bypass lymphatic obstructions
- Liposuction.

Patients for surgery need to be selected carefully and counselled to ensure realistic expectations of likely outcome. Maintenance of any improvement gained requires lengthy post-surgical compression therapy.

Potential indications for surgery in lymphoedema include:

- Severe deformity or marked disability due to swelling
- Removal of redundant tissue after successful conservative therapy
- Proximal lymphatic obstruction with patent distal lymphatics
- Lymphocutaneous fistulae and megalymphatics
- Eyelid and external genital lymphoedema
- Lack of response to compression therapy
- Recurrent cellulitis/erysipelas
- Intractable pain
- Lymphangiosarcoma.

### Palliative care

Palliative care is focused on providing patients with relief from symptoms such as pain, swelling, and psychological distress, rather than treatment of the underlying condition and its causes. The aim is to improve quality of life for both patients and family/carers.

The needs of patients with lymphoedema who are otherwise ill with advanced disease and who require palliative care are often complex. Patients who develop oedema at this stage in life may or may not have lymphatic failure but symptoms may develop quickly and cause considerable distress. Principles and elements of lymphoedema treatment may be very helpful in minimising distress and further complications. A lymphoedema practitioner or palliative care practitioner with knowledge and skills in relation to lymphoedema may make a useful contribution to the multidisciplinary team. The potential benefits of any treatment strategy must be balanced with the potential burden on the patient and be determined by patient-driven goals, e.g. maintaining mobility. It is essential for those involved to have an understanding of the pathophysiology and possible contributory factors to oedema and where possible to address any treatable causes. Regular assessment is also important as the situation may change rapidly.

Sensitive communication on the prognosis is essential in determining a flexible, agreed plan of care reflecting achievable goals. Lymphorrhoea is a common, distressing complication and should be treated as any other skin wound with appropriate dressings and light compression applied with bandaging and reapplied as necessary if there is leakage. Specialist compression garments may be helpful if the skin is intact. All compression requires modification and so should be under the guidance of a practitioner with adequate training in the assessment and fitting of these for lymphoedema.

Further information can be found in the International Lymphoedema Framework publication 'The Management of Lymphoedema in Advanced Cancer and Oedema at the End of Life' (2010).

## Recommendations

2	Health Boards should designate Leads for lymphoedema services who should be tasked with developing local pathways for the referral and management of lymphoedema based on existing evidence and guidance, to include management and prevention of cellulitis in people with established lymphoedema, and provision of advice on self management.
3	A SIGN guideline should be developed for the diagnosis, assessment and management of primary and secondary lymphoedema. SIGN should consider including lymphoedema in the remit when updating relevant cancer guidelines.
4	Healthcare Improvement Scotland should consider developing QPIs for the management of lymphoedema. Potential indicators could include: <ul style="list-style-type: none"><li>• referral to lymphoedema specialist services/clinics by board area, including type of lymphoedema, referral source, and age ranges to determine equity across the lifespan</li><li>• proportions of medical, nursing and AHP staff by board area who have had additional lymphoedema training</li><li>• numbers of diagnoses in primary and secondary care</li></ul>
5.	Scottish Cancer Taskforce should also consider lymphoedema outcomes when proposing updates for relevant sets of cancer QPIs.

## Section 3 – Providing a Multi-Agency Service

It is important that the multi-agency service has clearly identified core members with easy access to a much wider group of services that may be required. A named co-ordinator for each team should be identified.

### 3.1 Patient experience

Patients with lymphoedema experience significant physical and psychosocial burdens which are amenable to management interventions, with early interventions costing less than treatments for advanced lymphoedema. In addition to the provision of clinically effective interventions, reducing the adverse impact on the quality of life of a patient requires ongoing support in the community.

A recent poll of the top ten priorities of people with lymphoedema by Macmillan Lymphoedema Project Scotland (2013) found that patients and their carers place the highest value on:

- Getting the best treatment
- Receiving a prompt diagnosis
- Not having to wait long for my treatment to start
- Being able to access treatment quickly if my condition worsens
- Receiving prompt assessment and treatment if I have symptoms of cellulitis
- Being able to obtain replacement hosiery as required
- Accessing specialist lymphoedema care locally
- My GP knowing about my condition and treatment
- My lymphoedema care provider knowing enough about my condition and treatment and
- Being supported to self manage my lymphoedema.

### 3.2 Health and social care policy

In terms of health and social care policy in Scotland, the Healthcare Quality Strategy and the Route Map to the 2020 Vision for Health and Social Care state the Scottish Government is committed to “shift the balance of power to, and build upon the assets of, individuals and communities through a focus on achieving social change (more people able to care, volunteer etc.), support for the self management of long-term conditions and personal action (alcohol, exercise, diet and engagement) through working in partnership in Community Planning Partnerships (CPPs) and the new Integrated Health and Social Care Partnerships”.

The aims deliver the principles observed by the Christie Commission that “effective services must be designed with and for people and communities” (Scottish

Government, 2011). This is supported by the underlying principle of the Public Bodies (Joint Working) (Scotland) Bill 2013, that Health Boards and local authorities must take joint and equal responsibility for the delivery of nationally agreed outcomes for health and well being.

Evidence reviewed by the Health Foundation (2011) suggested that there are potential gains to be made from shifting some acute inpatient and day case services from hospital into the community. Those potential gains include better health outcomes for patients, greater patient satisfaction with services and more cost-effective delivery of treatment.

This shift from hospital to community supports the Long Term Conditions Collaborative Improving Care Pathways resource (Scottish Government, 2010), which promotes ten approaches by partnerships to deliver better outcomes and an enhanced experience of care for people living with long term conditions. Achieving better outcomes for people may involve shifting the location of care, sharing responsibility by empowering a different member of the multi-professional team, or shifting the focus of care through an anticipatory approach that prevents or delays dependency and need for more intensive support.

This approach also includes delivering care closer to home by providing as much care as possible in the community, including general practice and the wider primary care; making home care as safe, flexible, responsive and as enabling as possible; and developing the community hospital role which could be integrated or co-located with social care, housing support and third sector organisations.

### 3.3 Current service delivery

There is currently a wide variation in the organisation and delivery of lymphoedema services across Scotland. Some Health Boards provide a comprehensive service, whereas others offer services only for patients with cancer. Unfortunately, in some Health Boards there are no services available specifically for lymphoedema. In addition, the teams delivering lymphoedema care range from lone practitioners to small teams, with some or no administrative support, leading to variable waiting times and variable management options. It is also important to consider the location of these services as the location may not be acceptable to patients despite excellent service quality. For example, services located in hospices may not be acceptable to people who do not need palliative care.

The two main components of a comprehensive NHS Scotland service for people with lymphoedema should include:

1. Clinical intervention to manage the condition in addition to raising awareness among health and social care workers, patients, carers and the public. The aim is to improve the quality of life and enable individuals with the condition to function as independently as possible. This requires an integrated multidisciplinary and

multiagency team, including the voluntary sector, to address not just the clinical aspects of the condition, but also:

- health improvement, lifestyle and health promoting advice (such as smoking cessation, increasing physical activity, balanced diet and moderate intake of alcohol)
- prevention of ill health (such as prevention and early robust management of cellulitis or other associated conditions such as cardiovascular disease)
- psychological, emotional, psychosocial, educational, and spiritual care support.

This type of service needs to be equitable as well as of a high quality, accessible locally as much as possible, and culturally sensitive.

2. Adopting the model of long term conditions management and supported self management, which is ideally suited for this condition, where the care is delivered mainly in the community and primary care with access to various specialist services and care as appropriate. Mindful of mobility and access challenges for people with these conditions, some of these services could be shared-care with regionally based services such as for complex oedema (Tier 3 – see below and in Figure 2) or nationally for complex resistant lymphoedema; congenital/genetic lymphoedema, complex syndromes or lymphoedema in children; or those who require assessment for a surgical intervention. Shared care could include telehealth and telecare interventions as well as face-to-face interventions. A referral and management pathway for children’s services described in Appendix 4.

Needs can be usefully assessed according to tiers of care as outlined on page 20. This tiered approach has been adapted from the NHS Forth Valley Generic Care Pathway for long term conditions, which has been designed to promote an integrated and system-wide approach. At each tier of care, give consideration to:

- Where people receive information, including condition-specific information, information about services, and correspondence regarding appointments
- The level of intervention
- Care setting
- Partnership working
- Models of best practice
- Shared care.

## Application to Lymphoedema Services

### Stages of care

In long term conditions it is good practice to consider patients' needs along various stages of the pathway of care. For lymphoedema, these stages may be described as:

#### **Tier 0: For people who are well**

This level describes services provided at home and in community setting with and for people who are well. Services aim to inform and educate the general public about lifestyle choices and self management, raising awareness of how to identify early signs of lymphoedema and how to access services if needed. They may include targeted health improvement for those with higher risk of lymphoedema (e.g. cancer patients receiving surgical or radiotherapy interventions) as well as general health and wellbeing awareness.

#### **Tier 1: Development of symptoms**

This identifies those first level services provided to help people, who have developed symptoms, to manage their lymphoedema and maintain their health and wellbeing. The purpose is to enable speedy access to primary care services, facilitation of early diagnosis and staging of the condition where appropriate. Maximising quality of life and independence at home may require additional information and support to manage their condition from family, community and voluntary sector partners.

#### **Tier 2: Established lymphoedema with needs met fully in the community**

In this situation, services address the requirements of those individuals where the aim is to support people to manage their lymphoedema and maintain their health and wellbeing through primary care services, delivered with community and voluntary sector partners. Maximising quality of life and independence at home may require additional support from outreach rehabilitation, diagnostic, social care and housing services.

#### **Tier 3: Lymphoedema mainly managed in the community but require specialist input**

At this stage services are provided for people who are already supported by the primary care team, but who need additional intermittent and usually intensive support delivered by specialist lymphoedema practitioners. It is important to have effective coordination across multi-disciplinary and multiagency teams. It may useful to consider Anticipatory Care Planning at this stage, and explore carer support needs.

#### **Tier 4: Frequent exacerbations and people with most complex care needs**

These services apply to people with serious lymphoedema, with complex needs which may include other underlying long term conditions or difficulties. Services need to be well coordinated with timely access to a range of professionals, across care settings and agencies. As well as increased involvement of specialists based in hospitals or hospices there is a need to deliver effective packages of care and equipment that proactively and continually support people. This requires an integrated approach to care planning (including the appropriate use of telehealthcare), workforce development, and effective information sharing. For people who require inpatient hospital care, such as surgery, referral and admission criteria, should be agreed and known to practitioners. It is essential to have a well co-ordinated discharge plan prior to discharge of the individual into the community.

#### **Tier 5: End of Life Care**

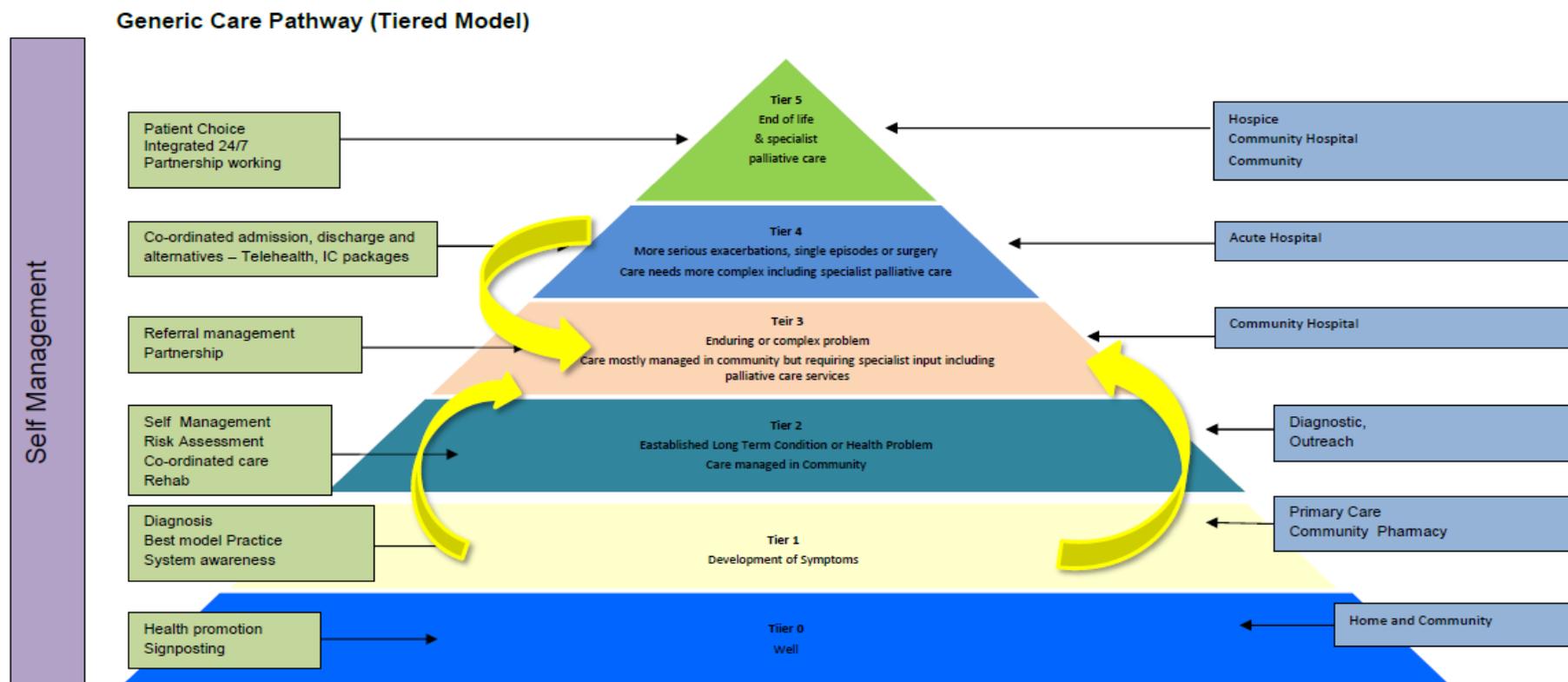
Here the services need to address the complex need of patients with advanced disease with palliative care requirements, and the needs of their informal carers. A variety of supportive measures and treatments from specialists, generalists and the voluntary sector may be helpful. The care, which is more appropriately delivered in community or hospice settings in the majority of cases, should be informed by the wishes of the individual and those close to them.

See Figure 2.

#### **Recommendations**

6	Health Boards should support and develop a community-based integrated model of tiered care for people with lymphoedema, including complications such as cellulitis applying the principles of integration.
7	Health Board Leads together with regional planning groups should develop a national referral pathway for people with lymphoedema who require assessment for surgery for lymphoedema.

Figure 2. Tiers of Care. Adapted from NHS Forth Valley LTC Collaborative.



**At each tier of care, give consideration to:**

- The level of intervention
- Care setting
- Partnership working
- Models of best practice
- Shared care

## Section 4 – Education, Training and Research of Health and Social Care Professionals

Research has highlighted a lack of awareness and knowledge of lymphoedema in health care professionals generally and a dearth of trained practitioners, with some Health Boards having little or no provision (Sneddon et al, 2008). To improve both quality of care and equity of access to care for the growing population of people with lymphoedema, as discussed in Section 1, and to adopt an anticipatory care approach with an aim of reducing incidence and severity, education at all levels is essential. The level of knowledge required by professionals who predominantly deal with those at risk of lymphoedema or whose needs are less complex will differ from those seeing people with complex or severe lymphoedema.

Needs are also context specific (Davies et al, 2012), so there are areas of care provision in which it may be appropriate to identify some individuals for whom it would be useful to develop knowledge or skills in particular aspects of lymphoedema treatment, but who do not require preparation as a specialist practitioner, e.g. in cancer centres where there is a concentration of people 'at risk' or with early lymphoedema.

The tables in Appendix 7 are broadly adapted from a model proposed by Sneddon (2007) to identify the levels of knowledge and skill required to meet patient needs in different contexts, with related competencies and suggested ways of learning. They also reflect what anyone with, or at risk of, lymphoedema should reasonably expect from the various health and social care professionals. Each part of the table indicates which outcomes might be expected from the various professionals in different contexts. The overarching outcomes to be expected from improved education and training are as follows:

- Prompt recognition of symptoms and signs suggesting lymphoedema
- Initiation of appropriate investigations to exclude or confirm diagnosis
- Prompt recognition and appropriate management of complications, including cellulitis and lymphorrhoea
- Management according to an agreed treatment pathway
- Referral onwards to specialist practitioner or surgical service where appropriate
- Support of self management for both prevention and long term maintenance to improve quality of life
- Seamless care in which patients are seen by the most appropriate health professional for the severity of their condition (see Tiers of Care p 20)
- Equity of provision of lymphoedema services across Scotland

These outcomes are synergistic with many of the top ten priorities of people with lymphoedema identified by the Macmillan Lymphoedema Project Scotland (2013) (Page 15 of this report).

They are consistent with the approach to maximise the potential for self management with professional support as close to the patient as possible. Nonetheless, all Health Boards should have provision for referral of people with complex lymphoedema, or during exacerbations of their lymphoedema, to a specialist service for advice or for more intensive or specialist treatment.

## Recommendations

8	NHS Education for Scotland should commission the development of basic multi-disciplinary educational modules in various formats for different professional groups – nurses, doctors, physiotherapists, podiatrists and social carers. Separate learning should be considered for non-registered staff, other associated health professionals as well as social carers as they have less background knowledge of the condition.
9	Health Boards should raise awareness of lymphoedema and cellulitis and pathways for their management amongst health and social care professionals through education and training.
10	All lymphoedema practitioners and specialists should have training in assisting individuals with lifestyle change.
11	<p>Research should be undertaken for lymphoedema treatment to:</p> <ul style="list-style-type: none"> <li>• analyse the cost and benefits of treatment versus no treatment,</li> <li>• estimate the burden of disease and</li> <li>• identify wasteful treatments and strategies or avenues for savings in relation to lymphoedema treatment particularly in relation to: <ul style="list-style-type: none"> <li>• provision of appropriate compression garments for each patient</li> <li>• prescription of ineffective treatments or unnecessary investigations and delays in treatment.</li> </ul> </li> </ul> <p>The CSO should consider proposals for research in these areas.</p>

## Section 5 – Recommendations

The previous sections outlined the key issues affecting the quality and equity of lymphoedema service provision in Scotland. The following recommendations have been developed to address these key issues. They are consensus-based and reflect the expert opinion of the SLWG.

1	<p>Health Boards should accurately identify incidence and prevalence of lymphoedema through improved coding at hospital discharge and in primary care.</p> <p>On confirmation of diagnosis the following READ codes are recommended:</p> <ul style="list-style-type: none"> <li>• G860. lymphoedema post mastectomy</li> <li>• G861. – other lymphoedema.</li> </ul> <p>ICD10 codes for lymphoedema: I89.0, I97.2, Q82.0 in any diagnosis position.</p>
2	<p>Health Boards should designate Leads for lymphoedema services who should be tasked with developing local pathways for the referral and management of lymphoedema based on existing evidence and guidance, to include management and prevention of cellulitis in people with established lymphoedema, and provision of advice on self management.</p>
3	<p>A SIGN guideline should be developed for the diagnosis, assessment and management of primary and secondary lymphoedema, to include prevention, early recognition and management of cellulitis in primary care. SIGN should consider including lymphoedema in the scope when updating relevant cancer guidelines.</p>
4	<p>Healthcare Improvement Scotland should consider developing QPIs for the management of lymphoedema. Potential indicators could include:</p> <ul style="list-style-type: none"> <li>• referral to lymphoedema specialist services/clinics by board area, including type of lymphoedema, referral source, and age ranges to determine equity across the lifespan</li> <li>• proportions of medical, nursing and AHP staff by board area who have had additional lymphoedema training</li> <li>• numbers of diagnoses in primary and secondary care, and</li> </ul>
5	<p>Scottish Cancer Taskforce should also consider lymphoedema outcomes when proposing updates for relevant sets of cancer QPIs.</p>
6	<p>Health Boards should support and develop a community-based integrated model of tiered care for people with lymphoedema, including complications such as cellulitis applying the principles of integration.</p>
7	<p>Health Board Leads together with regional planning groups should develop a</p>

	national referral pathway for people with lymphoedema who require assessment for surgery for lymphoedema.
8	NES should commission the development of basic educational modules in various formats for different professional groups – nurses, doctors, physiotherapists, podiatrists and social carers. Separate learning should be considered for non-registered staff as they have less background knowledge of the condition.
9	Health Boards should raise awareness of lymphoedema and cellulitis and pathways for their management amongst health and social care professionals through education and training.
10	All lymphoedema practitioners and specialists should have training in assisting individuals with lifestyle change.
11	<p>Research should be undertaken for lymphoedema treatment to:</p> <ul style="list-style-type: none"> <li>• analyse the cost and benefits of treatment versus no treatment,</li> <li>• estimate the burden of disease and</li> <li>• identify wasteful treatments and strategies or avenues for savings in relation to lymphoedema treatment particularly in relation to: <ul style="list-style-type: none"> <li>• provision of appropriate compression garments for each patient</li> <li>• prescription of ineffective treatments or unnecessary investigations and delays in treatment.</li> </ul> </li> </ul> <p>The CSO should consider proposals for research in these areas.</p>

## Abbreviations

AHP	Allied health professional
BLS	British Lymphology Society
CMO	Chief Medical Officer
CSO	Chief Scientist Office
CPP	Community Planning Partnership
CT	Computed tomography
GP	General practitioner
HCP	Health care professional
HCSW	Health care support worker
ISD	Information Services Division
MDT	Multi-disciplinary team
NES	NHS Education for Scotland
NHS	National Health Service
QPI	Quality performance indicator
SGHSCD	Scottish Government Health and Social Care Directorates
SIGN	Scottish Intercollegiate Guidelines Network
SLWG	Short life working group
SMASAC	Scottish Medical Advisor's Scientific Advisory Group

## Appendices

- Appendix 1 Membership of the Short Life Working Group
- Appendix 2 Additional Epidemiological Data
- Appendix 3 Case Histories
- Appendix 4 Referral and Management Pathway for Children Suspected to Have Lymphoedema
- Appendix 5 Information for Primary Care
- Appendix 6 Further Information and Guidance
- Appendix 7 Workforce Competencies and Educational Requirements

## Appendix 1. Membership of the Short Life Working Group

Name	Job title	Organisation
Dr John Gillies	Chairman	Royal College of General Practitioners Scotland
Dr Jim Beattie	Specialty Adviser Paediatric Medicine  Consultant Paediatric Nephrologist  Associate Medical Director	NHS Greater Glasgow and Clyde
Ms Yolande Borthwick	Scottish Lymphoedema Practitioners Network	University of Glasgow
Professor Julie Brittenden	Specialty Adviser, Vascular Surgery	University of Aberdeen
Diane Dempster	Business and Policy Support Officer	Scottish Government
Craig Fotheringham	Senior Orthotist	NHS Lothian
Ms Claire Hastie	Macmillan CNS, Lymphoedema	NHS Lothian
Ms Michele Hilton Boon	Programme Manager	Healthcare Improvement Scotland
Mr Colin Howie	Specialty Adviser Orthopaedics and Trauma  Consultant Orthopaedic Surgeon	NHS Lothian

Susan Kennedy	National Coordinator for General Practice Nursing	NHS Education for Scotland
Ms Heather Knox	Director of Regional Planning	NHS Forth Valley
Mr Andy Malyon	Specialty Adviser Plastic Surgery	NHS Greater Glasgow and Clyde
Dr Christine McAlpine	Specialty Adviser Geriatric Medicine  Consultant Stroke Physician	NHS Greater Glasgow and Clyde
Dr Mini Mishra	Senior Medical Officer	Scottish Government
Mr Alex Munnoch	Consultant Plastic Surgeon	NHS Tayside
Ms Amanda Platt	Project Manager Macmillan Lymphoedema Project for Scotland	Health and Social Care Alliance Scotland (the ALLIANCE)
Dr Clive Preston	Specialty Adviser Palliative Medicine	NHS Fife
Ms Margaret Reid	Team Lead Physiotherapist Lymphoedema and Palliative Care	NHS Fife
Ms Margaret Sneddon	Head of Nursing and Health Care School  Lead for Lymphoedema Education and Research College of Medical, Veterinary and Life Science	University of Glasgow
Dr Barry Vallance	Specialty Adviser Cardiology  Consultant	NHS Lanarkshire

	Cardiologist Lead Clinician for Heart Disease Scotland	
Dr Frances Yuille	Consultant Clinical Oncologist	NHS Lothian

## Appendix 2. Additional Epidemiological Data

Table 1 below shows Scottish hospital data for admissions with lymphoedema as the main diagnosis in calendar years 2002-2010.

Table 1. The number of hospital episodes for lymphoedema by NHS Health Board and Scotland level, calendar year 2002 - 2010									
	2002	2003	2004	2005	2006	2007	2008	2009	2010
<b>SCOTLAND</b>	<b>498</b>	<b>487</b>	<b>484</b>	<b>621</b>	<b>625</b>	<b>633</b>	<b>633</b>	<b>598</b>	<b>690</b>
NHS Ayrshire & Arran	56	47	45	36	68	52	54	57	68
NHS Borders	8	11	19	19	24	11	11	8	9
NHS Dumfries & Galloway	17	16	19	12	28	12	15	23	38
NHS Fife	50	36	40	55	32	38	80	82	87
NHS Forth Valley	45	21	26	14	13	20	9	24	20
NHS Grampian	59	71	47	33	58	58	80	38	82
NHS Greater Glasgow & Clyde	102	114	101	143	138	121	99	128	112
NHS Highland	38	49	46	51	39	67	59	42	35
NHS Lanarkshire	27	33	37	134	113	90	68	46	73
NHS Lothian	59	68	49	64	79	91	106	77	90
NHS Orkney Islands	2	0	27	28	16	49	30	49	54
NHS Shetland Islands	3	1	5	0	1	0	1	2	0
NHS Tayside	31	16	21	22	13	19	19	20	22
NHS Western Isles	1	4	2	10	3	5	2	2	0
Source: SMR01 (ISD Scotland) discharges from non-obstetric/non-psychiatric NHS hospitals in Scotland.									
ICD10 codes for lymphoedema: I89.0, I97.2, Q82.0 in any diagnosis position.									

The average length of stay was 8.59 days per person (range 1-287). The admission numbers recorded are considered an underestimate as poor diagnostic coding and poor awareness of the condition may omit many patients from these figures. The current cost per in-patient bed day is calculated at £491. Using this figure an estimate of costs in 2010/11 (1,436 bed days in total) can be calculated at a minimum of £705,076.

Table 2 below demonstrates variation in specialist staffing levels by health board. Some Health Boards provide services only for people with cancer related lymphoedema, whilst others provide a full service for all types of lymphoedema. Clinics range from lone part-time practitioners to small multidisciplinary teams and are based within palliative care centres, cancer clinics, physiotherapy departments, hospital and community based clinics. Referral pathways to services differ between Health Boards as do assessment processes and the co-ordination of treatment pathways.

Table 2. Specialist Lymphoedema Practitioners by Health Board Area	2012 Staff Levels	2012 WTE	2008 WTE ***
NHS Ayrshire and Arran**	1	0.5	0.8
NHS Borders	Nil return	Nil return	Nil
NHS Dumfries and Galloway	1	0.5	0.6
NHS Fife	2	2	0.6
NHS Forth Valley*	2	1.3	0.7
NHS Greater Glasgow and Clyde	5	4.43	3.3
NHS Grampian	4	1.8	1.9
NHS Highland	3	0.4	1.7
NHS Lanarkshire	3	1.4	0.6
NHS Lothian	10	3.43	0.2
NHS Tayside	2	1.35	1.4
NHS Western Isles	3	ns	0.5
<b>Total WTE</b>		<b>17.11</b>	<b>12.3</b>

\*\*\* Figures supplied for Strathcarron Hospice, Denny.

\*\* In addition, there are two non-funded ad-hoc services identified at Ayr Hospital and Ayr Central Hospital.

\*\*\* Obtained from analysis undertaken by Sneddon et al, 2008.

## Appendix 3. Case Histories

### Case history 1

The patient is a 55 year old woman, obese and diabetic, referred by her General Practitioner (GP) because of persistent leg swelling failing to respond to diuretics. The GP has not undertaken any investigations other than routine urea and electrolytes. The patient was referred with a diagnosis of resistant congestive cardiac failure.

When seen at the clinic the patient was noted to be very obese with a BMI of 41. She is very overweight and is of very short stature.

Examination revealed that there was no rise in the jugular venous pulse, that there was no hepatomegaly, her lung bases were clear but she had significant oedema of both ankles. This oedema was pitting.

Further investigation revealed normal renal function and normal serum proteins. An echocardiogram was performed which again was completely normal with normal right and left ventricular function and dimensions with no evidence of pulmonary hypertension.

**Clinical Diagnosis:** Dependent oedema, [at risk of lymphatic overload development of lymphoedema](#).

**Gold Standard Recommendations:** Compression therapy and weight reduction, plus education on her risk of lymphoedema and preventative strategies of activity, skin care, breathing exercises and leg elevation when seated. Ongoing management in primary care.

**Management:** The patient was advised to wear compression stockings. She was advised also to continue with low dose diuretic. She was referred to the dietician for dietary advice to lose weight.

The patient was reviewed in the clinic six weeks later with improvement in the leg oedema due to the use of compression stockings. Her weight, however, had not significantly changed. She was discharged from the clinic with advice to be followed up by the dieticians on a regular basis and for her GP to consider the use of weight reducing adjuncts such as appropriate drug therapy.

### Case history 2

The patient, a 75 year old man, was referred by his GP to the outpatient clinic because of chronic leg swelling. The GP described that his legs were inflamed and

occasionally weeping. These had not improved despite 80 mg of furosemide. The GP noted a past history of congestive cardiac failure and was concerned that the patient's leg oedema had not improved despite an enhanced diuretic dosage.

When seen at the clinic on examination the lower limbs were very heavy and oedematous with excoriation, scaling skin and redness over both shins. In addition the patient had evidence of right heart failure with raised JVP and some hepatomegaly.

Other examination was unremarkable.

Investigations included an echocardiogram which showed impaired right and left heart function. There was a moderate degree of pulmonary hypertension. Routine biochemical investigations showed a mild degree of renal impairment. Liver function tests were mildly abnormal in keeping with hepatic congestion but the serum proteins were normal.

**Clinical diagnosis:** chronic congestive cardiac failure (CCF). His legs, whilst showing some degree of pitting oedema, probably evidenced some development of **chronic lymphoedema consequent to severe heart failure** in the long term.

**Management:** As the patient had failed to respond to enhanced oral diuretic therapy he was offered admission for intensive intravenous diuretics. Following his admission with intensive diuretic therapy the leg swelling subsided. The patient was also treated with intravenous antibiotics with flucloxacillin as there was an element of cellulitis.

There was a mild degree of renal impairment which worsened with the intensive diuretic therapy but this again subsided on withdrawing the intravenous therapy and maintaining the patient on an enhanced dose of diuretic compared with prior to his admission.

The leg swelling persisted to some small degree suggesting a **mild degree of chronic lymphoedema**.

To reduce this patient's risk of worsening lymphoedema, the following care and interventions were required:

- Measurement for an appropriate compression garment and assessment of the patient's ability to apply a garment or availability of carers to assist with this
- Education on use and care of the garment
- Remeasurement and replacement of garment 4-6-monthly
- Verbal and written information on use and care of garment, skin care, physical activity, breathing exercises, diet, importance of prevention of infection,

including tinea pedis/trauma and early treatment with antibiotics if signs of cellulitis develop (see BLS Consensus on Cellulitis).

### Case history 3

The patient, a 54 year old woman, was referred by her GP to the outpatient clinic because of swelling of her left arm which had gradually increased over a period of 6-8 weeks. There was no associated discomfort.

There was no past history of note and in particular she had no past history of breast carcinoma.

On examination in the clinic she was noted to have a warm hand which was slightly dusky in colour. The pulses in the arm were normal and in particular the radial pulse was normal with good capillary refill.

The arm was swollen throughout its length and pitted only a little.

Other examination was unremarkable. In particular there was nothing to suggest underlying malignancy.

**Clinical diagnosis:** lymphoedema with a differential of possible axillary vein thrombosis.

Investigations with Doppler ultrasound and CT angiography demonstrated that the arterial supply to the arm was normal but that there was occlusion of the axillary vein.

The cause of this was uncertain. The patient had further investigations which revealed that she had a thrombophilia, i.e. an enhanced clotting state due to an inherited familial disorder.

**Management:** She was treated with anticoagulation initially with heparin and switched to warfarin. The arm swelling failed to improve with anticoagulation and the axillary vein remained occluded. She thus has **secondary lymphoedema** consequent to the axillary vein thrombosis and was subsequently referred to a lymphoedema specialist.

### Case history 4

The patient, a 35 year old man, was referred by his GP to the outpatient department because of chronic leg swelling. The GP also noted that the patient appeared slightly jaundiced.

When seen at the clinic a history of leg swelling developing over a three to four month period was noted as well as some abdominal swelling with the patient describing that his trousers had become tight at the waistband.

Physical examination revealed that the patient was mildly jaundiced, that there was significant hepatomegaly, with a small degree of the splenic enlargement and that there was significant ascites.

The lower limbs were swollen and the swelling was mildly pitting.

A social history was taken and it was discovered that the patient drank excess alcohol in the region of 60 units per week, primarily cider and fortified wine.

Abdominal ultrasound revealed a degree of hepatomegaly and significant ascites.

A Doppler ultrasound of the legs was performed and this was normal with no evidence of deep venous thrombosis.

Routine biochemistry revealed a very low albumin level and abnormal liver function tests with a raised gamma GT. The patient was also mildly anaemic with a raised mean corpuscular volume (MCV). These biochemical parameters were in keeping with alcoholic liver disease.

**Diagnosis:** Advanced alcoholic liver disease

**Management:** The patient's management was palliative. His ascites improved with the use of diuretics with a combination of loop diuretic and spironolactone.

The leg swelling persisted due to persistent low albumin level. Skin care and palliative lymphoedema bandaging has a role in maintaining mobility, preventing and managing lymphorrhoea and maintaining comfort and mobility as long as possible.

The patient's progress was poor in that he went on to develop progressive portal hypertension and had recurrent admissions with worsening ascites and peripheral oedema and eventually succumbed three years later from hepatic failure as he had continued to consume very large quantities of alcohol despite advice to the contrary.

#### Case history 5

A 62-year-old man, known to have metastatic carcinoma of the prostate with bone metastases and enlarged abdominal lymph nodes, required a left ureteric stent. He had received palliative radiotherapy to the pelvis (10 fractions). He presented to his GP with leg and genital oedema and was referred on to a lymphoedema specialist with **lymphoedema secondary to metastatic cancer**.

### Specialist Assessment:

Skin: Intact

Subcutaneous Tissues: Stemmer's Negative

Site: Swelling from digits to trunk

Shape: No distortion evident on measurement

Size: 26% excess limb volume

**Diagnosis:** Moderate lymphoedema secondary to metastatic cancer, complicated by extension to trunk and digits.

**Gold Standard Recommendations:** Intensive treatment, including lymphoedema compression bandaging and education and support for on-going self management.

### Management:

- Discuss diagnosis, treatment options, implications and expected outcomes with patient
- Assess patient's expectations, goals, level of understanding and his own or his carer's ability to manage on-going treatment
- Class II RAL standard compression tights
- Whittaker Pouch for scrotal oedema
- Patient taught penile bandaging
- ETO custom-made compression shorts
- Kinesiotape to trunk to facilitate drainage of truncal swelling
- Regular monitoring and renewal of garments until able to self-manage with bilateral Farrow Wrap, skin care, movement and breathing exercises

### Case history 6

A 63 year old woman with leg swelling was referred to the vascular clinic. A lymphogram demonstrated abnormal lymphatics in the calf, preventing knee contrast reaching the thigh. She was referred to a lymphoedema specialist with **primary lymphoedema**.

### Specialist Assessment:

Skin: Very dry but intact

Subcutaneous Tissues: Significant non-pitting fibrosis below knee, severe around ankle; Stemmer's Positive

Site: Swelling from digits to root of limb but not involving trunk

Shape: Distortion present on measurement

Size: 63% excess limb volume

**Diagnosis:** Severe primary lymphoedema complicated by fibrosis, distortion and digit swelling

**Gold Standard Recommendations:** Intensive treatment, including lymphoedema compression bandaging, MLD, exercise and skin care with education and support for on-going self management.

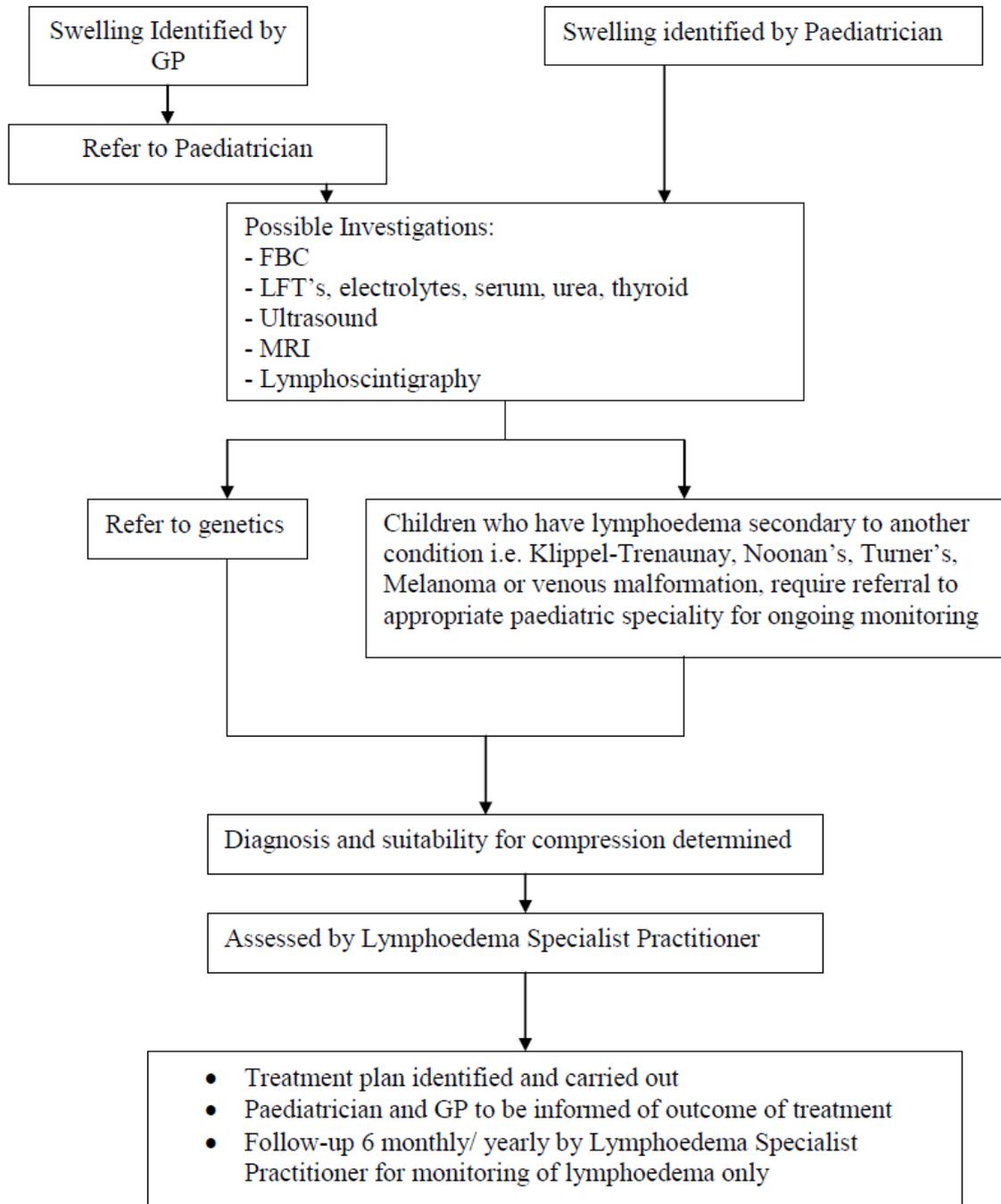
**Management:** 3 episodes of intensive treatment of 3 weeks each. Maintaining reduction between treatments was difficult, with excess volume fluctuating between 25 – 35%. Was referred for liposuction, which reduced excess volume to 9.9%, decreasing to -4%. Patient currently wears two thigh length stockings – a class I under a class IV RAL standard – to maintain reduction alongside standard maintenance self-care of exercise, skin care and simple lymphatic drainage/breathing exercise. She attends annual review.

#### Case history 7

A 58 year old woman developed right arm swelling. She had had a renal transplant and brachio-cephalic arterio-venous fistula which had occluded. Vascular investigations identified a narrowing of the subclavian vein. Subcutaneous tissue changes indicated a lymphatic problem and referral was made to a lymphoedema specialist. The patient had also developed a malignant melanoma of the left lower leg, which had been removed. She was under the care of the skin cancer clinic.

The long-term management of lymphoedema focused on limiting further deterioration of swelling, enhancing limb function and gaining long-term control of the condition. Support, education and encouragement are key to helping patients adjust to living with a long-term condition and maximising their ability to self-manage and achieve a sense of control.

#### Appendix 4. Referral and Management Pathway for Children Suspected to Have Lymphoedema



## Appendix 5. Information for Primary Care

Lymphoedema in Primary Care – Quick Guide	
Prevention	
<p>People at risk include:</p> <ul style="list-style-type: none"> <li>• Those with recurrent cellulitis</li> <li>• Inflammatory joint disease</li> <li>• Chronic skin problems</li> <li>• Trauma involving lymph nodes</li> <li>• Obesity</li> <li>• Family history of lymphoedema</li> <li>• Cancer and its treatment</li> <li>• Those with limited mobility.</li> </ul>	<p>Health care professionals should offer oral and written information to people at risk of developing lymphoedema on how to minimise their risk. Information should include:</p> <ul style="list-style-type: none"> <li>• Good skin care</li> <li>• Identifying infection</li> <li>• Physical activity</li> <li>• Weight management and a balanced diet.</li> </ul>
Recognition	
<p>People at high risk and their carers should be offered written and oral information on how to recognise the common signs and symptoms of lymphoedema:</p> <ul style="list-style-type: none"> <li>• Swelling (is often presenting in one limb)</li> <li>• Change in sensation (feels heavy, tight, full, stiff)</li> <li>• Skin change (tight, stretched).</li> </ul>	<p>Primary health care professionals should be able to recognise the signs and symptoms of lymphoedema in order to differentiate diagnosis from recurrence of malignancy, deep venous thrombosis, or cardiac failure. If lymphoedema is suspected early referral to a health care professional with specialist knowledge of lymphoedema for diagnosis, assessment and treatment is recommended.</p>
<p>On confirmation of diagnosis the following READ codes are recommended:</p> <ul style="list-style-type: none"> <li>• G860. lymphoedema post mastectomy</li> <li>• G861. other lymphoedema.</li> </ul>	
Treatment	
<p>Following assessment from a health care professional with specialist knowledge of lymphoedema the treatment and support for self management can be provided in primary care:</p> <ul style="list-style-type: none"> <li>• Psychosocial support</li> <li>• Self monitoring of lymphoedema signs and symptoms</li> <li>• Encouraging daily skin care, limb elevation and lymphatic drainage as taught by health care professional with specialist knowledge of lymphoedema</li> <li>• Monitoring compression treatment and prescribing.</li> </ul>	

Cellulitis is a common complication and needs to be assessed and treated vigorously to prevent further lymphatic damage and worsening of lymphoedema. Guidelines on treatment are available from <http://www.thebls.com/consensus.php>.

#### Follow-up

Lymphoedema is a long term condition requiring primary care practitioners to have appropriate knowledge and skills so as to support people and their carers to self manage. Access to a practitioner with specialist knowledge is required if the condition deteriorates requiring reassessment.

GP Notebook <http://gpnotebook.co.uk/homepage.cfm> offers a useful summary of diagnosis and management in primary care.

## Appendix 6. Further Information and Guidance

Detailed international and national guidance is available for professionals from the [International Lymphoedema Framework](http://www.lympho.org) (www.lympho.org), [British Lymphology Society](http://www.thebls.com) (www.thebls.com) and [Lymphoedema Scotland](http://www.lymphoedema-scotland.org) (www.lymphoedema-scotland.org).

Patient specific information is available from the [Lymphoedema Support Network](http://www.lymphoedema.org) (www.lymphoedema.org), [Macmillan Cancer Support](http://www.macmillan.org.uk) (www.macmillan.org.uk; this is cancer specific) and [NHS Inform](http://www.nhsinform.co.uk/cancer/treatments/lymphoedema) (www.nhsinform.co.uk/cancer/treatments/lymphoedema).

Information on generic resources for self management and supported self management can be obtained from the [Health and Social Care Alliance for Scotland](http://www.alliance-scotland.org.uk/what-we-do/self-management) (the ALLIANCE; www.alliance-scotland.org.uk/what-we-do/self-management). Lymphoedema-specific self management information is available via the Macmillan Lymphoedema Project for Scotland [Top Tips for the Self Management of Lymphoedema – A Guide](#). The Guide was co-created with people living with lymphoedema over two workshops and postal responses during Lymphoedema Awareness Week 2012. The Guide is also accessible via the Macmillan Cancer Support Lymphoedema webpages and NHS Inform.

Generic learning resources for healthcare workers to develop knowledge and understanding to support self management are available from NHS Education for Scotland: <http://www.nes.scot.nhs.uk/education-and-training/by-theme/initiative/self-management/supporting-self-management.aspx>. BMJ Learning has produced a module on lymphoedema: <http://learning.bmj.com/learning/home.html>

‘GauN Yersel’ A Self Management Strategy for Scotland was launched in 2008 in partnership between the Scottish Government and the Long Term Conditions Alliance for Scotland. The strategy states that partnership with the individual is central to self management during five key life stages: diagnosis, day to day living, progression, transitions and end of life. GauN Yersel recognised that successful self management depends on professionals understanding and enabling a person-centred approach in which the individual is the leading partner in managing their own life and condition(s). <http://www.scotland.gov.uk/Publications/2008/10/GauNYersel>.

The Lymphoedema Support Network (LSN) is a national UK charity which provides the largest information resource to support people with lymphoedema, including fact sheets, self management DVDs and a regular newsletter (www.lymphoedema.org). It also promotes a network of support groups across the UK and has an on-line community, the Lymphoedema Support Network (<http://lsn.healthunlocked.com/>), which enables people to get answers to their health questions from other people living with lymphoedema, thereby supporting self management.

In addition to the above lymphoedema-specific information, generic self management information was developed by the Health and Social Care Alliance for Scotland's (ALLIANCE) My Condition, My Terms, My Life Campaign. This campaign aims to help improve public understanding of what self management means for people living with long term medical conditions and encourages people with long term medical conditions, and the people looking after them, to adopt a self management approach. <http://www.myconditionmylife.org/>.

Lymphoedema Scotland (<http://lymphoedema-scotland.org>) provides advice for professionals on how they can provide self management support. Information on offer includes skin care and cellulitis, compression garments, movement and exercise, massage, and weight and lymphoedema. The site also provides links to other useful resources including the British Lymphology Society ([www.thebls.com](http://www.thebls.com)), which has a large amount of information and resources for professionals (NB membership is required to access some resources).

Empowering Cancer Nurses in Europe (EONS) (<http://www.cancernurse.eu>) is a pan-European organisation dedicated to the support and development of cancer nurses. Through their individual members and national societies they engage in projects to help nurses develop their skills, network with each other and raise the profile of cancer nursing across Europe.

Spring Soiree Event Report: Developing a Vision and Priorities for Lymphoedema Care in Scotland (2013). Health and Social Care Alliance Scotland/Macmillan Cancer Support. Available at:- <http://www.alliance-scotland.org.uk/what-we-do/projects/macmillan-lymphoedema-project-scotland/>

## Appendix 7. Workforce Competencies and Educational Requirements

Table 1

Key outcomes to be achieved	Reduce incidence, severity and complications, ensure early diagnosis, support self management and enhance quality of life	
Members of the health and social care team responsible	Suggested competencies	Educational requirement in relation to lymphoedema
All registered health care professionals (HCPs) in all settings	<p>Identify individuals who are at risk of lymphoedema</p> <p>Advise on general and specific lymphoedema risk reductions strategies</p> <p>Recognise signs of early lymphoedema</p> <p>Recognise signs of cellulitis and refer for assessment and treatment promptly when suspected</p> <p>Direct individuals to appropriate information and resources</p> <p>Be sensitive to concerns and understanding of needs</p> <p>Support individuals to manage their own care as far as they are able</p>	<p>Short term:</p> <ul style="list-style-type: none"> <li>• Communication strategy to raise awareness; online modules relevant to particular groups</li> <li>• General awareness raising locally re referral pathways and sources of expertise, information and support</li> </ul> <p>Long Term:</p> <p>Basic information integrated at key points in UG education for all HCPs on: lymphatic system, its function re lymphoedema, who is at risk, what they can do to minimise risk, clinical signs of lymphoedema and cellulitis</p>
Non-registered health and social carers, particularly in primary care or care of older people	<p>Implement skin care to protect its integrity and prevent cellulitis</p> <p>Reporting swelling or infection promptly</p> <p>Encourage movement and elevation of lower limbs when seated</p> <p>Support individuals to manage their own care as far as they are able</p>	Basic preventative care integrated into training

Table 2

<p>Key outcomes to be achieved</p>	<ul style="list-style-type: none"> <li>• Anticipate, reduce risk, recognise and treat lymphoedema of mixed origin</li> <li>• Anticipate, prevent and manage specific complications arising in lymphoedema or advancing illness to maximise quality of life, including lymphorrhoea and other skin problems</li> </ul>	
<p>Members of the care team responsible</p>	<p>Suggested competencies</p>	<p>Educational requirement in relation to lymphoedema</p>
<p>Lymphoedema champions particularly in primary care, elderly care and palliative care settings responsible for individuals with chronic lower limb oedema or requiring end of life care</p>	<p>Recognise and treat chronic oedema of mixed origin (venous, lymphatic, multi-organ failure)</p> <p>Recognise and address treatable contributory factors</p> <p>Implement appropriate skin care, activity/positioning and education to minimise risk of infection, lymphorrhoea, ulceration and trauma</p> <p>Apply appropriate dressings and compression if swelling or lymphorrhoea develops</p> <p>Involve lymphoedema practitioners for advice on helpful strategies</p>	<p>Short modules, possibly on-line or blended and as part of specialist palliative care courses</p> <p>Specific professional or context based on-line resources/podcasts e.g. for podiatrists</p> <p>Opportunities for experience of patients in a lymphoedema clinic with periodic updates</p>

Table 3

Key outcomes to be achieved	Routinely screen, monitor and support self management as part of an agreed prevention protocol OR as part of a long term maintenance programme, under supervision/support of an appropriately trained registered HCP	
Members of the care team responsible	Suggested competencies	Educational requirement in relation to lymphoedema
Health Care Support Workers (HCSWs) Band 3-4 or registered practitioners in key roles/settings where there is increased risk or incidence of lymphoedema, e.g. in oncology OR where there is increased incidence of chronic oedema, e.g. in oncology , elderly care or primary care settings OR in a specialist lymphoedema clinic	<p>Provide specific Information and advice to at risk individuals or those with lymphoedema</p> <p>Measure limb volumes</p> <p>Undertake standardised assessment procedures</p> <p>Fit and replace compression garments in those meeting agreed criteria or those whose lymphoedema/chronic oedema is stable</p>	<p>Short training module, blended online/face to face with mentorship and supervision until agreed level of competence achieved</p> <p>Periodic review of skills</p>

Table 4

<p>Key outcomes to be achieved</p>	<ul style="list-style-type: none"> <li>• Assessment of individuals to confirm presence of lymphoedema and agree a plan of treatment with the patient</li> <li>• Undertake management according to an agreed treatment pathway for uncomplicated lymphoedema</li> </ul>	
<p>Members of the health and social care team responsible</p>	<p>Suggested competencies</p>	<p>Educational requirement in relation to lymphoedema</p>
<p><b>Lymphoedema Practitioner</b> in particular settings/roles whose regular exposure to people with lymphoedema would allow development of confidence and competence, e.g. oncology, paediatrics, care of older people, dermatology, vascular services</p>	<p>Comprehensive assessment of individuals with lymphoedema including assessment of limb volume and skin and tissue changes in order to stage it.</p> <p>Supervise HCSWs with a lymphoedema role</p> <p>Make decisions to refer for further investigations or more specialised treatment where required</p> <p>Support self management, monitor effects of treatment</p> <p>Liaise with Lymphoedema Specialist and refer on as required for advice and specialist treatment during periods of exacerbation/poor control of condition but taking lead role if condition is stable with optimum self management according to agreed pathway</p> <p>Ensure a multidisciplinary approach to maximise potential for self-care, e.g. weight management, social care, housing</p>	<p>Recognised course – blended face to face, online and workbased with recognised qualification</p>

Table 5

<p>Key outcomes to be achieved</p>	<ul style="list-style-type: none"> <li>• Initiate appropriate investigations to exclude or confirm diagnosis of lymphoedema when necessary and to identify other co-existing morbidities</li> <li>• Ensure involvement of Lymphoedema Practitioner if there is evidence of lymphatic insufficiency</li> <li>• Initiate prompt treatment for cellulitis</li> </ul>	
<p>Members of the care team responsible</p>	<p>Suggested competencies</p>	<p>Educational requirement in relation to lymphoedema</p>
<p>General Practitioners and Consultants in specialties associated with higher prevalence of lymphoedema, e.g. oncology, vascular medicine, dermatology, cardiology, care of older people</p>	<p>Recognise early signs of possible lymphoedema</p> <p>Refer for appropriate assessment or investigations and advice from specialist practitioners when appropriate</p> <p>Follow BLS guidelines or locally adapted protocols for treatment and prevention of cellulitis</p>	<p>Awareness of clinical features and progression of lymphoedema</p> <p>Awareness of cellulitis treatment and prevention protocols</p> <p>Awareness of principles of treatment of lymphoedema and how to access treatments</p> <p>Information integrated into key points of UG curriculum. Short term need for awareness raising, possibly through online module</p>

Table 6

Key outcomes to be achieved	Equitable provision of lymphoedema services	
Members of the care team responsible	Suggested competencies	Educational requirement in relation to lymphoedema
Lymphoedema Specialist Practitioner*	<p>Manage all types of complex or unstable lymphoedema with degree of autonomy and responsibility for own caseload within an MDT context</p> <p>Supervise and guide/advise other HCPs and HCSWs</p> <p>Selected services/practitioners should accept referrals for treatment of children or act as consultants to paediatric services</p>	<p>Degree level education plus specific qualification in specialist lymphoedema management</p> <p>Opportunity to gain clinical experience in treatment of children with lymphoedema</p>
Lymphoedema Advanced Practitioner*	<p>Manage and lead developments of lymphoedema service while having a key clinical and educational role</p> <p>Support and act as a resource for lymphoedema practitioners and specialist practitioners</p>	<p>Highly developed clinical professional and theoretical knowledge to at least Master's level</p> <p>Recognised qualification in Specialist/Advanced Lymphoedema management</p> <p>Training in comprehensive clinical examination skills</p>
Clinical Leads/Case Managers in MDT	<p>Ensure lymphoedema practitioners are involved/consulted as part of an MDT approach to managing care for people with complex lymphoedema or lymphoedema alongside other co-morbidities.</p>	<p>Awareness of the principles of lymphoedema treatment and risk reduction strategies</p> <p>Online education module</p>

\*Most likely to be registered nurse, physiotherapist or occupational therapist

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