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# Lymphoedema Referral and Management Guidelines

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# 1 Introduction

Cancer related lymphoedema is a consequence of cancer and its treatment, caused by an interruption to the lymphatic system. The incidence of lymphoedema is increasing, despite the increase in lymph node preserving treatment innovations. It is well documented that most, if not all, cancer patients are all at risk of developing lymphoedema either because of the cancer itself or the treatment used to cure or control the cancer spread (BLS 2013, ILS 2010). The lymphoedema may not be visible for some time and can occur many years later; therefore patients remain at risk for the rest of their lives (ISL 2009).

Lymphoedema is a distressing, debilitating chronic incurable condition causing physical and psychological problems for the person affected and requires lifelong management (BLS, 2010). It is not possible to prevent it completely; however, identifying those most at risk is essential in order to empower patients to take control in preventative care. The consequences of not doing so for the patient can be devastating.

The British Lymphology Association (BLS) and International Lymphology Society (ILS) advocate that there is a clear pathway for referral and early management to maximise efficacy of intervention.

Evidence suggests that early intervention can be cost effective and improve patient experience. *Specialist Lymphoedema Support Services; an evidence review* (Macmillan, 2011) states that ‘for every £1 spent on lymphoedema services, by limiting swelling and preventing damage and infection, the NHS saves £100 in reduced hospital admissions’. Untreated lymphoedema can result in cellulitis leading to hospital admissions and drug costs which could be avoided. Life-long management also requires a constant need for expensive compression hosiery.

The LCA Lymphoedema Community of Practice (CoP) mapped current service availability in 2013, and following on from that work, committed to developing a clear pathway for care, encompassing the whole patient journey. This includes prevention, early identification and management, later and more intensive intervention and clear referral and discharge criteria. The aims of this document are to:

- Outline the agreed pathway
- Define the best practice interventions at each stage, based on best available evidence and expert clinical consensus where the evidence is not as strong
- Define referral criteria to lymphoedema services
- Identify areas where this will require alterations to current service provision
- Identify how those alterations can be implemented
- Provide details of the LCA Lymphoedema CoP agreed standardised outcome measures and metrics

## 2 Risk Factors

### 2.1 Cancer

Some cancers spread to the lymphatic system while others cause pressure on the lymphatics and surrounding tissues. This leads to reduced transport capacity and disruption to the fragile network of lymphatic vessels. Those cancers most likely to cause lymphoedema are breast, melanoma, gynaecological, prostate, penile, bladder, sarcoma and head and neck cancers (BLS 2010).

### 2.2 Cancer treatment

#### **Surgery**

Surgery to remove the cancer can cause damage to the lymphatic pathway particularly when lymph nodes are removed. Those who develop post-operative wound infections, seromas or haematomas, or other complications which delay healing are more at risk of developing lymphoedema. More extensive surgery increases risk of lymphoedema developing.

## Radiotherapy

Radiotherapy causes scarring and further disruption to the lymphatic pathway. It is the most common cause of breast and truncal swelling. It affects the movement of the tissues in the affected area and can result in loss of movement and peripheral nerve damage. Lack of movement is a known risk factor for developing lymphoedema.

## Chemotherapy

Some agents, particularly taxanes, cause peripheral neuropathy and peripheral digit swelling. Vesicants can cause localised tissue damage affecting the lymphatic pathway. Some anticancer agents can cause metabolic disturbances which will also have an effect on the lymphatic system, e.g. non-steroidal anti-inflammatories and anti-oestrogens.

## 2.3 Other

### Obesity

Obesity causes increased capillary filtration which then increases pressure on the lymphatic system (Loffler, 2002). Being overweight has a detrimental effect on the successful outcome of treatment (Loffler, 2002, BLS, 2013). Compression garments are less effective as fat acts as a buffer against pressure, there is poorer blood supply, and the fit of the garments can be compromised. Obese patients tend to be less active, and it is well-known that exercise is important in controlling the swelling (BLS, 2013).

### Immobility

Immobility causes sluggish blood flow and increased pressure on the lymphatic system. Those with nerve damage causing brachial plexus neuropathy are particularly prone to lymphoedema (BLS, 2013).

### Medical conditions

Venous/arterial insufficiency, cellulitis, inflammatory conditions, e.g. arthritis, uncontrolled skin problems such as psoriasis, eczema, and fungal infections, obesity, heart, renal or liver failure, metabolic disturbances and approaching end of life, are all known to increase lymphoedema risk (ISL, 2009).

Emerging research suggests that some people have a predisposition to developing lymphoedema. This may be because they either are born with or subsequently develop reduced lymphatic capacity.

## 3 Pre-Cancer Treatment

### 3.1 Pre-treatment limb measurements

Pre-treatment limb measurements provide an objective way to monitor changes in limb volume over time as well as providing a means of evaluating outcomes of treatment.

#### 3.1.1 Circumference

It is known that left/right limb circumference can be different even before cancer treatment. This means that without pre-surgical measurements, there is no way of telling whether equal circumference post-operatively shows change or no change i.e. presence or absence of lymphoedema.

Specialist lymphoedema professionals use limb volume measurements including the Kunkhe method, where volumes are calculated at 4cm intervals to provide an overall limb volume measurement that can be divided into proximal and distal volumes/ratios. While this method is frequently used by lymphoedema specialists (who should work to an agreed protocol), there is concern about the reproducibility of this technique amongst other healthcare workers, resulting in inaccurate measurements.

### Recommendation

To facilitate consistency and accuracy of pre- and post-operative measurements carried out by members of the MDT, it is recommended that a simple format be implemented that is easily reproducible enabling a high level of accuracy between practitioners repeating measurements on different patients and at different time points (Appendix 1).

### Outcome

Recording measurements as outlined above, supports early identification of onset of lymphoedema with prompt referral to specialist lymphoedema services when needed. Research has shown that timely specialist intervention can help to reduce co-morbidities associated with lymphoedema helping to improve the patient's quality of life and reduce costs to the NHS.

## 3.2 Patient information and consent

It is known that people who have treatment such as surgery and radiotherapy for certain cancers (including breast, gynaecological, urological, head and neck and skin), are at an increased risk of developing lymphoedema. These patients need to know why they are at risk, the implications of being at risk, what they can do to minimise the risk of developing lymphoedema and what action they should take if swelling develops (BLS 2010). Pre-treatment information about how to reduce their risk of developing lymphoedema and actions to take if they identify problems with swelling should be incorporated into the consent process.

### Recommendation

Those at risk of developing lymphoedema as a consequence of their cancer treatment should have this explained to them as part of the consent process. This should be supported by the provision of written information.

## 4 Risk Factor Management

There is international consensus that proactive management of risk factors to minimise the chances of lymphoedema developing in those at risk is effective. This involves provision of risk factor management information, day-to-day lifestyle choices and routine self-monitoring for early signs of lymphoedema.

### 4.1 Provision of information

Information should be given at four points:

- prior to cancer treatment; see section 3.2 'Patient information and consent'
- in a treatment summary for those whose cancer and its treatments put them at risk (see LCA survivorship guidelines or LCA tumour specific guidelines for treatment summary details)
- as part of a health and well-being event for those with tumours which have a known risk of lymphoedema (breast, gynaecological, urological, head and neck) (see LCA survivorship guidelines or LCA tumour specific guidelines for treatment summary details)
- in a lymphoedema prehabilitation course for those at high risk.

All risk factor management information should cover three key areas:

- exercise
- maintaining a healthy weight
- skin care

It should also include being alert to early signs of lymphoedema such as heaviness, aching in a limb, or transient swelling.

The aim of prehabilitation, a precursor to rehabilitation, is to help individuals make an informed choice about their treatment programme to help maximise their potential (David, 1993: 132). A long standing programme in Wales, run at Abertawe Bro Morgannwg University Health Board, has shown a reduction in incidence of lymphoedema following treatment for breast cancer from 1 in 3 to 1 in 12 over the last 10 years.

The success of interventions for lymphoedema is dependent on the person's long term compliance with advice and their ability to make informed decisions related to their daily management programme (Farncombe et al 1994). Education provided about lymphoedema risk management should support the ethos that where patients proceed to develop lymphoedema, the aim from the outset is to help individuals work towards independent management; where this is not possible models of care need to be in place.

### Recommendation

Once first-line cancer treatment has finished, those living with and beyond the cancer and their primary care team should be given information in various forms to support this proactive risk minimisation and to facilitate early recognition of signs and symptoms and rapid referral for specialist intervention.

## 4.2 Exercise

There is wealth of evidence that exercise helps recovery from cancer treatment, can enhance feelings of well-being, maintain functional ability and reduce long term morbidity and all-cause mortality (Speck, Courneya et al (2010)). The NHS now recommends that all cancer survivors meet the same physical activity guidelines as the general population.

Evidence also supports the premise that normal physical activity/exercise helps to stimulate lymph flow. Getz (1985) found that patients who underwent a mastectomy and then took part in an active exercise programme had a lower incidence of lymphoedema than those patients who were not provided with exercise information. It has recently been shown, contrary to previous suggestion, that resisted exercise does not increase the risk of lymphoedema.

### Recommendations

Exercise should be encouraged for those at risk of, or with lymphoedema.

Those who have an impairment which impacts on their functional ability, or their ability to participate in exercise, e.g. reduced shoulder range of movement, should be referred for assessment by a physiotherapist.

Those with other LTCs (long term conditions) which impact on their ability to exercise, e.g. cardiovascular disease, should be referred via their GP to locally available exercise initiatives, such as exercise on prescription.

## 4.3 Weight management

Body weight is an important factor for patients with lymphoedema, as being overweight or obese increases the risk of lymphoedema developing (Helyer, Varnic et al. 2010). Women with a BMI over 30 have a significantly higher risk of developing lymphoedema in the two years after surgery compared to those with a BMI less than 25 kg/m<sup>2</sup>.

For those who are overweight and in whom lymphoedema has developed, dietary counselling or referral for weight management should be considered as part of their overall management plan. Weight reduction has been shown to provide additional benefit and reduce arm volume in women fitted with compression hosiery or undergoing compression bandaging (Shaw, Mortimer et al. 2007).

A study conducted by Bertelli et al (1992) documented a negative response to treatment over a period of six months in patients who gained weight and did not wear hosiery for a minimum of six hours a day; in those who did not gain weight, there was a 25% reduction in swelling (Bertelli, Venturini et al. 1992).

Patients should be made aware of the negative impact that being overweight can have on control of lymphoedema as well as the impact on their general health and well-being. General advice about healthy eating should be available within lymphoedema services, with onward referral to a dietitian or weight management group initiated where further support and information and assessment is needed to achieve and maintain weight reduction.

#### Recommendation

General advice about healthy eating should be available within lymphoedema services.

Onward referral to a dietician should be initiated where the patient needs further advice, support and information in order to achieve and maintain weight reduction.

## 4.4 Skin care

The accumulation of lymphatic fluid in the interstitial spaces provides an ideal breeding ground for bacteria. This means that minor skin damage, for example as the result of a small scratch, can result in an infection. Infection can result in cellulitis, with repeated infections causing further damage to the lymphatic system, making the development of lymphoedema more likely.

#### Recommendation

Verbal and written information about how to look after skin to prevent damage and infections should be given.

Information about what to do if worried that an infection has developed should also be provided.

## 5 Assessment

### 5.1.1 Bio-impedance spectroscopy

Bioelectrical impedance analysis (BIA) measures the impedance or opposition to the flow of an electric current through the body fluids, contained mainly in the lean and fat tissue. Impedance is low in lean tissue, where intracellular fluid and electrolytes are primarily contained, but high in fat tissue. Impedance is thus proportional to body water volume. In practice, a small constant current, typically 800  $\mu$ A at a fixed frequency, usually 50 kHz, is passed between electrodes spanning the body and the voltage drop between electrodes provides a measure of impedance. It can therefore be used to measure subclinical changes in extra cellular fluid.

Cornish (1996) demonstrated that bio-impedance spectroscopy is significantly more sensitive than circumferential measurement both in the early diagnosis of lymphoedema and in monitoring change.

Hayes (2008) found a difference in the amount of fluid between affected and unaffected arms in 60% of breast cancer patients who had been 'missed' by arm circumference measurements and concluded that bioimpedance spectroscopy is more sensitive in the clinical assessment of patients post breast cancer treatment than circumferential arm measurements.

### 5.1.2 Perometry

Perometry measurement of limb volume uses non-invasive, opto-electronic imaging to measure the limb volume of legs or arms. Quick and easy to use following training, it can provide data on limb size and shape and can also guide the therapist in the size of garment. It requires a dedicated clinical space as the

equipment is not portable and on-going maintenance costs need to be considered when allocating resources following purchase.

Studies by Stanton (1997) and more recently by Bulley et al (2013) have confirmed reliability, but some standardisation of the approach to measuring between different therapists is required.

### 5.1.3 Water displacement

Limb volume measured using Archimedes' principle of water displacement has historically been considered the gold standard of volume measurement approaches (Bernas et al 1996).

A cylindrical container is used to immerse the limb in a carefully measured quantity of water and the displaced water indicates the volume of the limb. An advantage of this technique is that the volume of the feet/hands can be included. The distribution of the oedema throughout the limb cannot be established and the technique can be difficult to complete with less agile patients. Consideration also needs to be made to the temperature of the water and infection control.

### 5.1.4 Tape massessment

See section 3.1.1 Circumference

## 6 Diagnosis

Diagnosis is based on past medical history and completion of a comprehensive physical and psychosocial assessment. Lymphoedema practitioners work in close liaison with the multi-professional team enabling access to further investigations and assessment, when needed. This is particularly important when lymphoedema assessment reveals a possible underlying pathology.

## 7 Treatment

The presence of lymphoedema represents the 'end stage failure of lymph drainage' (Mortimer, 1990:8). It is important that action is taken to help control swelling and prevent the development of co-morbidities.

There is clear guidance in Figure 6 of The Lymphoedema Framework Consensus Document (2006) on the appropriate treatment for the four stages of lymphoedema (see Appendix 2). A treatment regimen will always involve assessment and management of the four main approaches to the management of lymphoedema which are:

- skin care and cellulitis prevention
- exercise
- lymphatic drainage
- compression therapy (bandaging and hosiery).

The aims of any lymphoedema management programme are:

- to stabilise and ideally reduce the limb volume and address any skin changes
- to ensure that the patient and their family are empowered to manage the lymphoedema proactively
- to liaise with community services to ensure a smooth transition of care from tertiary to primary care or to achieve a multi-disciplinary approach to support the patient and their family long-term.

## 7.1 Skin care

Daily skin care is essential for patients with lymphoedema to help minimise the risk of them developing cellulitis and other chronic skin changes associated with lymphoedema. Cellulitis can cause further damage to an already compromised lymphatic system and if not treated appropriately can lead to septicaemia.

All lymphoedema specialists can identify skin changes and conditions frequently associated with lymphoedema. If the treatment of these conditions cannot be managed within the lymphoedema service, patients should be referred to the appropriate team for treatment, including dermatology, primary care, and oncology.

### Recommendations

Those with lymphoedema should be provided with clear information, both verbal and written, about daily skin care management and how to seek help if they notice signs of, e.g. cellulitis.

There should be clear locally agreed pathways between the lymphoedema service and their onward referral destinations.

## 7.2 Exercise

See section 4.2

## 7.3 Lymphatic drainage

The drainage of lymphatic fluid in a swollen limb or area of the body can be encouraged by a sequence of specialised hand movements performed on the skin. The aim of these movements is to stimulate the movement of lymph away from a congested area towards an area of normal lymph drainage. Evidence of the efficacy of lymphatic drainage remains unproven but symptomatic benefit has been widely reported, particularly when lymphatic drainage is used in conjunction with other approaches to treatment.

There are two approaches to lymphatic drainage:

- manual lymphatic drainage (MLD)
- simple lymphatic drainage (SLD)

As part of maximising skin integrity and reducing limb volume, therapists may also use some newer technologies such as Hivamat electrotherapy, laser therapy and/or intermittent pneumatic compression pumps in addition manual lymphatic drainage techniques to help promote lymph drainage.

Having encouraged lymph flow and, ideally, reduced the limb volume, compression is applied.

### **7.3.1 MLD**

Performed by a skilled therapist, the aim of MLD is to increase activity within functioning lymphatics so that lymph fluid can be encouraged with specialised hand movements, to drain more effectively from swollen areas. A skilled therapist has knowledge of the correct movements to encourage the lymphatics to open and drain; the appropriate sequence and number of hand movements required; and the correct pressure to apply to the skin.

### **SLD**

Based on the principles of MLD, this approach to lymphatic drainage uses simplified and modified skin movements so that it can be self-administered by the patient. SLD should always be taught to patients by therapists with appropriate training. Patients' understanding of the technique is enhanced when they have previously experienced MLD by a skilled therapist.

### Recommendation

There should be access to skilled MLD therapists within each lymphoedema service and SLD should be taught to support ongoing maintenance of limb volumes when necessary.

## 7.4 Compression therapy

Compression can be applied either as round knit or flat knit hosiery or as multi-layer bandages. There are various bandaging systems which are used depending on the shape and functionality of the limbs and whether or not the bandaging will continue to be applied by community nurses in the longer term for ongoing management. Some practitioners are only able to use products which are available on prescription (FP10) and this too will impact upon the choice of hosiery and bandages selected. Where garments are available on prescription the therapist, in conjunction with the hosiery company, should assist the patient and their GP in finding the correct garment on the NHS formulary and ensuring that the patient receives the correct garment from the pharmacy. Where garments are not available on FP10, patients will need to attend the clinic every six months for re-assessment of their limb size before their garments are ordered again.

### Recommendations

Access to intensive bandaging should be available when needed.

A range of compression garments should be made available to those who need them, with clear and agreed ways of ensuring ongoing prescription within primary care. There should be easy access back to the lymphoedema services when revision of a prescription is needed.

## 8 Psychosocial Issues

Lymphoedema is a chronic condition which can be very responsive to pro-active management but it is not curable. It therefore has a psychological impact and can affect body image and functionality. The onset of lymphoedema can increase the fear of recurrence of cancer and can be a cause of psychological problems for this group of patients (Miller, 1994).

People living with lymphoedema may present with emotional issues related to an altered body image which can lead to loss of self-esteem and have a negative impact in other areas of life (Woods et al, 1995).

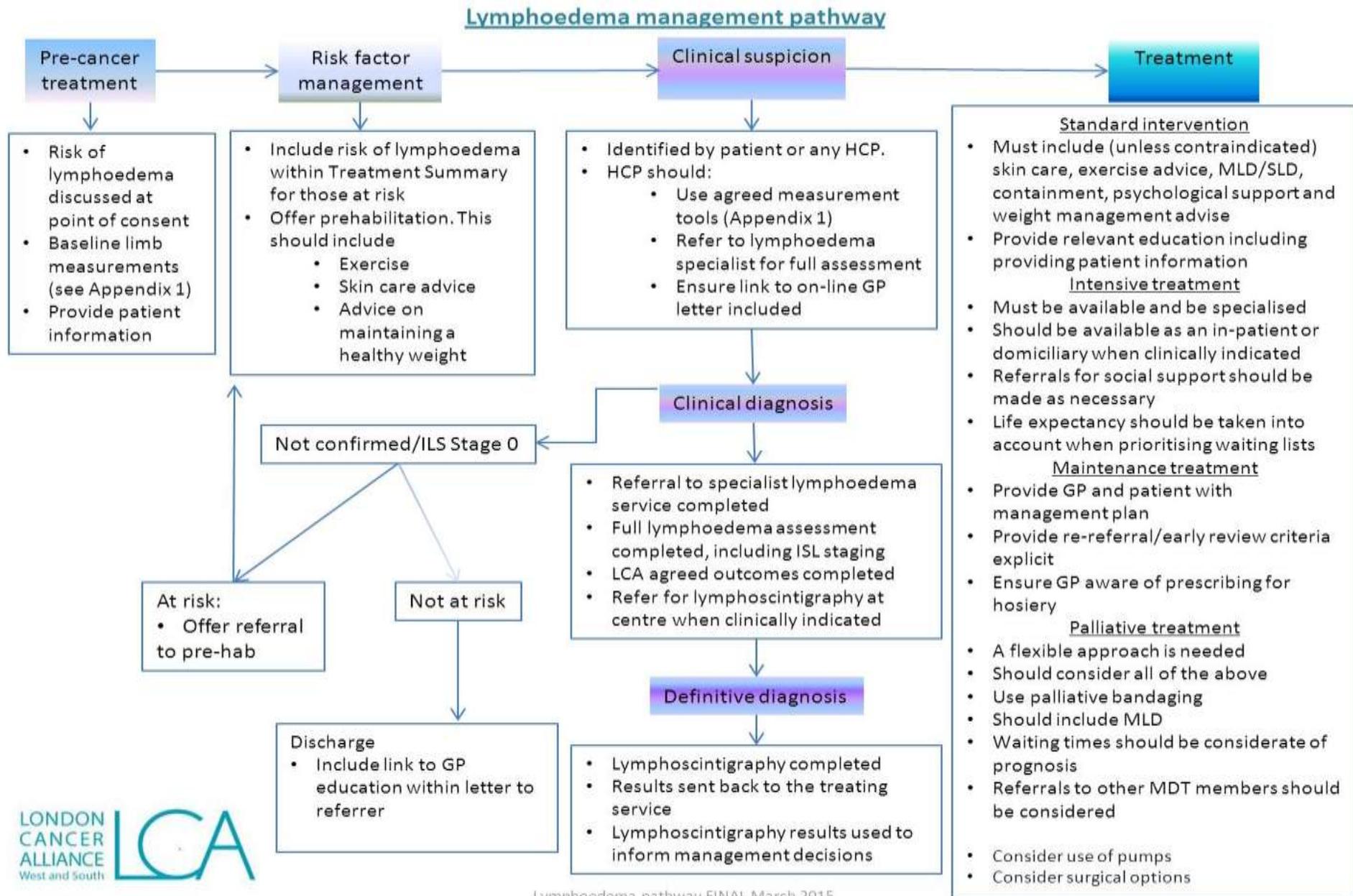
Lymphoedema can be a constant reminder of the original cancer diagnosis and the impact this can have on an individual's quality of life should not be underestimated. It is essential that a psychosocial assessment is an integral part of ongoing monitoring of the patient's progress, with onward referral to other members of the MDT as appropriate.

### Recommendations

Use of screening tools for psychological distress, such as a Holistic Needs Assessment (HNA), should be used as a routine part of assessment, with onward referrals made as needed.

Use of patient reported outcome measures should be part of routine practice within the lymphoedema services across the LCA.

## 9 Lymphoedema Pathway



## 10 Summary

This document lays out the LCA Lymphoedema CoP agreed lymphoedema pathway, associated evidence base and recommendations.

The evidence base is clear – proactive risk factor management of lymphoedema results in minimisation of the risk of lymphoedema developing. When lymphoedema develops, early intervention improves outcomes (financial, clinical and patient reported) and improves patient experience.

In addition to the recommendations listed, and summarised in Appendix 3, the following actions are also now needed:

- agreement of minimum content for lymphoedema information provision
- development of a lymphoedema module for health and well-being events
- collaborative work with LCA member Trusts, and other lymphoedema service providers, alongside commissioner to develop a prehabilitation pilot with clear plans for further implementation if successful
- implementation of use of agreed outcome measures (see Appendix 3) with audit across the LCA
- development of a service specification to support the implementation of these guidelines, including discharge criteria
- work alongside commissioners to establish improved garment prescription protocols
- work alongside training and education providers to support the development or roll-out of lymphoedema specific education, for both specialist and non-specialist lymphoedema professionals.

## Appendix 1: Limb Measurement Points

### Lower limbs

With the limb in a relaxed position, measure circumference:

- of the foot (at the 5<sup>th</sup> metatarsal head)
- 2cm above the medial malleolus
- 10cm above the superior pole of the patella
- 10cm below the inferior pole of the patella
- repeat with the other limb

### Upper limbs

With the limb in a supported position and the arm straight, measure circumference:

- around the dorsum of the hand (hand placed on a flat surface, fingers held together, tape placed at the base of the thumb joint in the web-space)
- around the wrist (2cm above the ulnar process)
- 10cm below the point of the elbow (olecranon process)
- 10cm above the olecranon process
- repeat with the other arm



## Appendix 2: ISL Lymphoedema Staging (International Society of Lymphology 2009)

### ISL stage 0

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

### ISL stage I

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

### ISL stage II

Limb elevation alone rarely reduces swelling and pitting is manifest.

### ISL late stage II

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

### ISL stage III

The tissue is hard (fibrotic) and pitting is absent. Skin changes such as thickening and hyperpigmentation.

## **Severity of unilateral limb lymphoedema (BLS)**

### Mild

<20% excess limb volume

### Moderate

20-40% excess limb volume

### Severe

>40% excess limb volume

## Appendix 3: Recommendations

- To facilitate consistency and accuracy of pre- and post-operative measurements carried out by members of the MDT, it is recommended that a simple format be implemented that is easily reproducible enabling a high level of accuracy between practitioners repeating measurements on different patients (Appendix 1).
- Those at risk of developing lymphoedema as a consequence of their cancer treatment should have this explained to them as part of the consent process. This should be supported by the provision of written information.
- Once first-line cancer treatment has finished, those living with and beyond the cancer and their primary care team should be given information in various forms to support this proactive risk minimisation and to facilitate early recognition of signs and symptoms and rapid referral for specialist intervention.
- Exercise should be encouraged for those at risk of, or with, lymphoedema.
- Those who have an impairment which impacts on their functional ability, or their ability to participate in exercise, e.g. reduced shoulder range of movement, should be referred for assessment by a physiotherapist.
- Those with other LTCs (long term conditions) which impact on their ability to exercise, e.g. cardiovascular disease, should be referred via their GP to locally available exercise initiatives, such as exercise on prescription.
- General advice about healthy eating should be available within lymphoedema services.
- Onward referral to a dietician/nutritionist should be initiated where the patient needs further advice, support and information in order to achieve and maintain weight reduction.
- Verbal and written information about how to look after skin to prevent damage and infections should be given.
- Information about what to do if worried that an infection has developed should also be provided.
- Those with lymphoedema should be provided with clear information, both verbal and written about daily skin care management and how to seek help if they notice signs of e.g. cellulitis
- There should be clear locally agreed pathways between the lymphoedema service and their onward referral destinations.
- There should be access to skilled manual lymphatic drainage (MLD) therapists within each lymphoedema service and simple lymphatic drainage (SLD) should be taught to support ongoing maintenance of limb volumes when necessary.
- Access to intensive bandaging should be available when needed.
- A range of compression garments should be made available to those who need them, with clear and agreed ways of ensuring ongoing prescription within primary care. There should be easy access back to the lymphoedema services when revision of a prescription is needed.
- Use of screening tools for psychological distress, such as Holistic Needs Assessment (HNA) should be used as a routine part of assessment, with onward referrals made as needed.
- Use of patient reported outcome measures should be part of routine practice within the lymphoedema services across the LCA.

## Appendix 4: LCA Agreed Outcome Measures and Key Performance Indicators for Lymphoedema Services

- LymQoL (upper or lower limb specific)
- Limb volumes
- Incidence of cellulitis pre- and post- treatment
- Number of GP visits for lymphoedema related issues pre/post treatment where this is currently collected
- Presence/absence of lymphorrhoea pre- and post-treatment
- Skin condition