LONDON CANCER ALLIANCE LCA

Lymphoedema Service Specification

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Contents

Contents 2
1 Introduction 3
2 Background 3
3 Standards 4
4 Service Outline 4
4.1 Staffing 4
4.2 Space 5
4.3 MDT working 5
4.4 Education and training 5
4.5 Service evaluation and audit 5
5 Interventions Which Should be Available 6
6 LCA-Agreed Outcome Measures 7
7 Key Performance Indicators 7
8 LCA Minimum Datasets 7

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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 cancer related lymphoedema is increasing, despite the increase in lymph node preserving treatment innovations. It is well documented that most, if not all, cancer patients are at risk of developing lymphoedema either because of the cancer itself or the treatment used to cure or control the cancer spread. 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.

It has long been established that lymphoedema service provision within England is sub-optimal, and that the cost of continued failure to provide the necessary services has a significant impact on the health economy, the wider economy and the person's health and quality of life.

UK national consensus standards of practice for people with, or at risk of, lymphoedema, were published in 2003, with International Consensus Best Practice guidelines published in 2006. National strategies for lymphoedema services were published in Wales in 2009, Northern Ireland in 2010 and Scotland in 2013. England currently does not have a national strategy, though the development of such was strongly recommended by the Lymphoedema Reference Group, working through the National Cancer Action Team in 2012.

2 Background

The LCA Lymphoedema Community of Practice (CoP) was established in 2013. It mapped lymphoedema service availability within the LCA in 2013 and established that availability was inconsistent and inequitable. The mapping showed that many referrals were being made when lymphoedema was well established and so needed specialist input.

A review of the service mapping in 2015 showed that the situation had not changed, and that access remained inequitable. However, referral numbers had gone up and the case mix had changed, with more gynaecological and head and neck cancer related lymphoedema being referred..

Subsequent to the 2013 mapping, the CoP worked to identify training and education needs of the expert practitioners within the LCA, as well as to establish training and education that they would be confident and competent to provide to non-lymphoedema specialists.

In 2015 the Community of Practice published the LCA Lymphoedema Referral and Management Guidelines June 2015. These laid out the expectation that cancer service providers would provide information at key points to help both healthcare professionals and people affected by cancer to recognise early signs and symptoms of lymphoedema, would proactively monitor for early signs, and would know how and when to make onward referrals to expert services.

This document seeks to specify what LCA-based lymphoedema services should reasonably be expected to provide and the measures by which they should be monitored. It focuses specifically on services for people who develop lymphoedema following a cancer diagnosis and treatment, but may be equally applicable to those with primary or other cause lymphoedema.

3 Standards

The UK Lymphoedema Framework includes six standards for lymphoedema services and as such form the basis for LCA lymphoedema service provision.

1. **The identification of people at risk of, or with, lymphoedema**

Systems to identify people at risk of or with lymphoedema, regardless of cause, will be implemented and monitored to ensure that patients receive high quality education and lifelong care.

2. **Empowerment of people at risk of, or with, lymphoedema**

Individual plans of care that foster self-management will be developed in partnership with patients at risk of or with lymphoedema (involving relatives and carers where appropriate), in an agreed format and language.

3. **Provision of integrated community, hospital and hospice based services that deliver high quality clinical care that is subject to continuous improvement**

All people at risk of or with lymphoedema will have access to trained healthcare professionals, including lymphoedema specialists, who will work to agreed standards for comprehensive ongoing assessment, planning, education, advice, treatment and monitoring. Care will be of a high standard and subject to continuous quality improvement.

4. **Provision of high quality clinical care for people with cellulitis/erysipelas**

Agreed protocols for the rapid and effective treatment of cellulitis/epysipelas, including prevention of recurrent episodes, will be implemented and monitored by healthcare professionals who have completed recognised training in this subject.

5. **Provision of compression garments for people with lymphoedema**

Agreed protocols of assessment and the provision of compression garments for people with lymphoedema, will be implemented and monitored.

6. **Provision of multi-agency health and social care**

Following comprehensive assessment, any patient at risk of or with lymphoedema who requires multi-agency support will have access to and receive care appropriate to their needs from health and social services.

4 Service Outline

4.1 Staffing

Services should be adequately staffed to provide assessment and intervention to their local populations. Cancer treatment centres (CTC) need to meet the requirements of the local population as well as meeting the demands of patients referred from out of area who are on the cancer treatment pathway.

Staffing must include degree-level qualified therapists, i.e. lymphoedema experts and dedicated administration support. It may also include manual lymphatic drainage (MLD) therapists, who should work under the supervision of a degree level qualified therapist, providing intervention as per the treatment plan designed by the qualified therapist.

The role of the administrator is likely to go beyond a traditional administration post, and include tasks specific to lymphoedema, such as stock monitoring for garments; managing bookings for patients requiring intensive treatment; PA tasks associated with helping specialists to fulfil their role. Some clinical skills may be required, e.g. taking height and weight.

4.2 Space

Lymphoedema clinics need dedicated clinical space. Many of the assessment methodologies require equipment which is bulky and heavy and therefore cannot easily be moved around and stored. In addition, manual handling issues associated with bandaging heavy, oedematous limbs are ameliorated by the use of appropriate clinical couches which also cannot easily be moved or stored.

4.3 MDT working

The lymphoedema team needs to ensure strong working relationships with the wider multi-professional team in order to be able to make timely referrals for lymphoedema related complications or alternative specialist advice, e.g. where symptoms raise concerns about recurrence of disease; for management of cellulitis or for cancer-specialist exercise/rehabilitation input.

4.4 Education and training

4.4.1 Qualification

All specialist lymphoedema staff must be qualified in line with *Best Practice for the management of lymphoedema* (2006)

All MLD therapists should have certified accreditation from one of the recognised courses below:

- Casley-Smith
- Foeldi
- FG-MLD
- Vodder

4.4.2 Teaching

Lymphoedema expert practitioners are expected to provide (non-accredited) teaching to the wider clinical team, i.e. to non-lymphoedema experts such as breast cancer CNSs and phlebotomists. This should include providing a continuous programme of teaching on pre-surgery measurement techniques as per the LCA's Lymphoedema Referral and Management Guidelines.

Lymphoedema expert practitioners may be part of organising and teaching on accredited courses as agreed within their services and associated higher education institutes (HEIs).

All members of the lymphoedema service are expected to remain up-to-date with current evidence and to be competent to provide their services, in line with their professional registration requirements.

4.5 Service evaluation and audit

All specialist lymphoedema services should strive to ensure they are providing an effective service. As such, a process of continued audit should be integral to its ethos. When variation is noted, or minimum standards are in danger of not being met, service improvement options should be investigated and piloted. The services should be providing evidence-based interventions, and as the evidence base grows, should be supported to pilot new initiatives.

5 Interventions Which Should be Available

Intervention	Assessment/Prevention/ Treatment	Essential/Optional	Rationale
Tape measurement	Assessment	Essential	Used to record surface measurements of a limb. When both limbs are measured, it is an objective way of determining if swelling is present, or if limb size has changed since a previous measurement
Skin care	Prevention/Intervention	Essential	One of the cornerstones of treatment. Good skin hygiene reduces the risk of complications such as cellulitis
Exercise	Prevention/Intervention	Essential	One of the cornerstones of treatment. Stimulates lymph flow.
Simple lymphatic drainage (SLD)	Intervention	Essential	Simplified version of MLD (see below) which patients can do themselves, but must be taught by an expert to ensure safe, appropriate technique
Manual lymphatic drainage (MLD)	Intervention	Essential	Increases activity within functioning lymphatics, and allows swelling to be moved and drained through these away from the affected area
Compression therapy	Intervention	Essential	Applies graduated compression to the oedematous limb to help contain and control swelling; to enable optimal function
Kineseotape	Intervention	Essential	Helps stimulate drainage of lymph away from the affected area
Intermittent pneumatic compression (IPC)	Intervention	Optional	As an adjunct to other forms of lymphoedema management to enhance the therapeutic response (Szuba 2002)

Bio-impedance spectroscopy	Assessment	Optional	More sensitive than circumferential measurement in early stages and for monitoring
Perometry	Assessment	Optional	Quick and easy to use, providing data on shape as well as size of limb
Water displacement	Assessment	Optional	Gold standard for measuring limb volume

6 LCA-Agreed Outcome Measures

- LymQoL Upper limb (http://oregon.providence.org/~/media/files/providence%20or%20migrated%20pdfs/patients%20toolkit/rehablymqolarm.pdf)
- LymQoL Lower Limb (http://oregon.providence.org/~/media/files/providence%20or%20migrated%20pdfs/patients%20toolkit/rehablymqolleg.pdf)
- Reduction and control of limb volumes

7 Key Performance Indicators

- Cellulitis in the year pre- and post- treatment
- GP visits for lymphoedema-related issues pre-/post- treatment
- Hospital admissions for cellulitis pre-/post- treatment
- Waiting times met. When necessary, quarter on quarter improvement demonstrated

8 LCA Minimum Datasets

- Numbers of new referrals
- Primary diagnosis, e.g. breast cancer
- Referral mechanism
- Pre-/post- intervention presence of lymphorrhoea
- Improved skin condition