

Lymphoedema Working Group

Model of Care
Survey results and recommendations

Background

- ▶ A meeting was held between Lymphoedema Ireland and the HSE in 2015. It was agreed to establish a Working Group to look at a Model of Care for **lymphoedema and lipoedema** and the provision of compression garments.
 - ▶ The HSE Lymphoedema Working Group was established in January 2016.
- 

Lymphoedema Working Group

- ▶ Chair person: Mr Brian Murphy,
- ▶ Representation from;
 - HSE acute hospital services
 - Community services
 - National Cancer Control Program.
 - HSE Community Funded Schemes Service Improvement Programme

Goals

- ▶ To develop a **model of care** for lymphoedema/lipoedema treatment services in the HSE based on international standards.
 - ▶ To develop **National Standards** for the provision of lymphoedema garments based on best practice guidelines.
- 

Work to date

- ▶ Project manager, Kay Morris; commenced September 2016.
 - ▶ A **national survey** was completed to look at the current services provided by the HSE. This included nursing, physiotherapy, occupational therapy and private therapists funded by the HSE
- 

- ▶ A **review of services** in other countries was completed to look at models of care
 - ▶ Review of **best practice literature** including the ILF consensus document (2006) and CREST guidelines (2008). Best practice for lipoedema (2017).
 - ▶ DCU study 2010
 - ▶ A preliminary **review of the education** provided at undergraduate level was completed.
- 

- ▶ A **procurement evaluation group (PEG)** is established to standardise the provision of compression garments and establish contracts for garments

Survey results

There were **43 surveys** issued.

- ▶ Total of **27 services** responded
 - 19 responses through survey monkey
 - 8 received through email.
- ▶ Difficult to define dedicated hours in most services as it varied from week to week and hours are estimated.

Survey results - Acute services

- ▶ **14 services in acute** hospitals-
 - 5 provide treatment for all oncology patients,
 - 2 for breast care only
 - 6 oncology and non oncology related lymphoedema
 - 1 lower limb only

Survey results -primary care services

13 services in all CHOs

- ▶ 7 in CHO 1
- ▶ CHO 2 has an oncology service only
- ▶ CHO 3, 6, 7 and 9 do not have a service

Survey results-Service providers

Lymphoedema services are provided by;

- ▶ physiotherapy (52%)
- ▶ nursing (20%).
- ▶ Some services are provided by a combination of disciplines (28%); Donegal networks are provided by physiotherapy and nursing and SIVUH and CUH have a physiotherapy and occupational therapy service.

Level of service

- ▶ **23 services provide intense treatment and maintenance**
 - ▶ **4 provide maintenance treatment only**
 - ▶ 3 of the 4 services that provide maintenance treatment have fully trained staff but do not have resources to provide intense treatment.
- 

Current staffing levels

- ▶ **72 specialist lymphoedema therapists** across Ireland working in the HSE.
 - ▶ **57 in general lymphoedema** services
 - ▶ **15 in palliative** services.
 - ▶ The number of trained specialist staff is high in some areas but the hours dedicated to lymphoedema is low.
- 

- ▶ The estimated total number of dedicated hours is **322.5 per week**
 - ▶ This equates to **9 WTE**
 - ▶ Hours range from 2 per week to 37 per week
 - ▶ This equates to an average of **6 hours per week** per therapist.
 - ▶ **3 therapists work in a full time** lymphoedema post
- 

Palliative care

- ▶ There are 10 hospices in the country and 5 provide lymphoedema services.
 - ▶ Of the 5 that do not have a service;
 - 1 contracts a private therapist
 - 4 refer to local hospital services.
 - ▶ There are 4 physiotherapists in home care teams;
 - CHO 8 (Louth and Meath)
 - CHO 1 (Cavan/Monaghan) garments and advice only
 - CHO 1 (Donegal) 1 physiotherapist in primary care
- There are no HSE palliative care lymphoedema services in CHO 2 or CHO 5.

Palliative care continued

- ▶ 15 trained lymphoedema therapists in palliative care with an estimated 80 dedicated hours per week, this equates to 2 WTE.
 - ▶ The services based in homecare could not estimate hours per week as this varied depending on the case load.
- 

Compression garment provision

- ▶ Variation of **1, 2 or 4 per year per patient** depending on the service.
 - ▶ Provision of garments varies between community and acute services, with more patients self-paying for garments in the community compared to acute services.
- 

Waiting times

- ▶ From the survey, waiting times vary across the country;
 - **1 week to 2 years for non-oncology** related lymphoedema
 - **1 day to 6 months for oncology** related lymphoedema.

Service access

- ▶ 87% of services accepted referrals from oncology (which would be expected as the majority of services are for oncology related lymphoedema only).
 - ▶ 17% of services took referrals from GPs, minority of services are in primary care.
 - ▶ Some services also accepted referrals from AHP's (45%), vascular services (37%), PHN (33%), dermatology (25%) and self-referral (20%).
- 

Standards/Guidelines

- ▶ From the survey 29% of services indicated that they used standards for treatment.
 - ▶ Standards that are used are not consistent
- 

Support services

- ▶ 41% tissue viability nurse
- ▶ 41% dietician
- ▶ 25% vascular services
- ▶ 12% dermatology
- ▶ 12% clinical psychology
- ▶ 12% obesity clinic
- ▶ 8% genetic services

Services are available but the survey would indicate that therapists are not aware of access or considered waiting times a barrier.

High risk patients

- ▶ From the survey 54% of services did not identify high risk patients.
 - ▶ The services that did identify high risk patients were primarily oncology services.
- 

Treatment Abroad Scheme and Cross Border Directive

- ▶ The TAS and CBD services are expensive compared to local services and are not sustainable for patients with chronic disease where care should be on going and available locally for support and self management.

Current lymphoedema undergraduate education

- ▶ Nursing- one hour taught on a post graduate diploma in oncology nursing
 - ▶ Physiotherapy; 18 hours UCD, 1 hour Trinity, 2 hours RCSI, case study UL.
 - ▶ Occupational Therapy; 2 hours UL
- 

Recommendations Overview

- ▶ Patient centred care
 - ▶ Integrated approach with specialist services and maintenance treatment in primary care and in reach to acute centres
 - ▶ Services for all types of lymphoedema
 - ▶ MDT
 - ▶ Dedicated resources based on population needs
 - ▶ Phased in implementation plan
- 

- ▶ Prevention, awareness education and screening tools in all high risk areas
 - ▶ Introduction of a minimum data set
 - ▶ National standards
 - ▶ Standardised outcomes measures
 - ▶ Guidelines for the prescription of compression garments.
- 

An overall education plan nationally for 3 levels of training;

- Specialist
- Non specialist
- Awareness and education

Research opportunities to be explored with universities to improve lymphoedema and lipoedema care, establish an accurate demand for services and ensure value for money

Next steps

- ▶ Finalise model of care
 - ▶ Seek approval
 - ▶ Funding
 - ▶ A phased in implementation plan
 - ▶ National standards need to be set
 - ▶ A national lymphoedema service forum
- 

Summary

- ▶ The existing services in Ireland are inequitable, untimely and not standardised.
- ▶ There is no consistency across services with variation in;
 - Type of lymphoedema accepted for treatment
 - Treatment provided,
 - Compression garment provision
 - Support services
 - Risk identification.

Summary continued

- ▶ There are skilled therapists in the work force, with some areas having more than adequate trained staff for the population demand but there is a lack of dedicated hours made available
 - ▶ There are areas of good practice in the country which could be replicated with standardisation, leadership and resources.
- 

Future vision for lymphoedema services

- ▶ A comprehensive lymphoedema and lipodema service of the highest standards with evidence based prevention and early detection; treatment and support; education and research.
 - ▶ An integrated model of care that enables equal access, timely assessment, appropriate treatment in the right setting with skilled staff.
- 

- ▶ The model of care is dynamic and will require revision and updating in the future as new research emerges e.g diagnostic techniques and surgical advancements.

