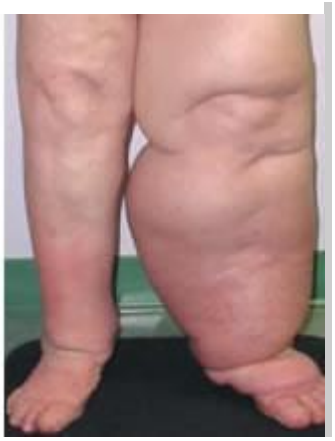
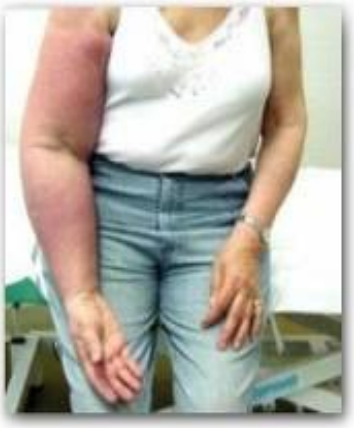




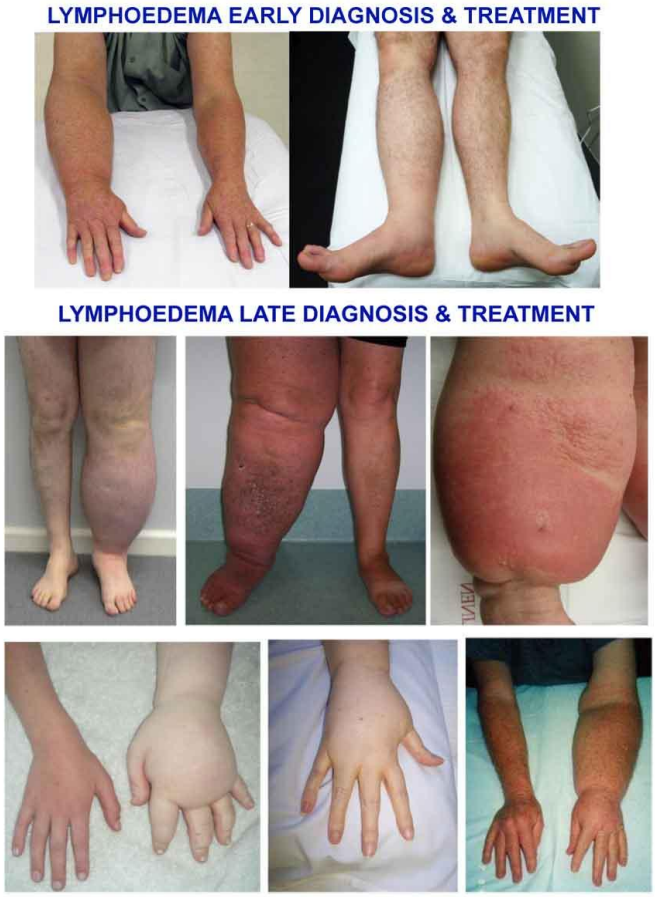
Lymphoedema
IRELAND

# Submission to the Expert Panel on medical need for medical card eligibility

**30 June 2014**

**Lymphoedema is a chronic, incurable and debilitating condition that can have serious impacts on the quality of life of people with the condition. If not treated effectively, consequences include long term disability, serious infection, reduced quality of life, emotional problems and problems at work.**

***Lymphoedema Ireland*** **recommends that patients with lymphoedema are granted a medical card on the basis of their medical and social service needs arising from their condition.**




## Overview

***Every patient with lymphoedema should have access to standardised, effective multi-disciplinary treatment for the condition.***

*Lymphoedema Ireland,* a volunteer patient-led national network that offers support, help and information to anyone in Ireland affected with lymphoedema, is grateful for the opportunity to bring lymphoedema to the attention of the Expert Panel considering eligibility for medical cards on medical grounds.

Lymphoedema is a progressive chronic condition that affects a significant number of people and can have harmful effects on patient's physical and psychological health as well as placing them at increased risk of life-threatening infection. Even though it may be greatly improved with appropriate treatment and day to day self-management, many patients are not told of their risk of developing lymphoedema, do not receive adequate treatment, are unable to afford to pay for expensive private treatment, and as a result are experiencing significant deterioration in their conditions and quality of life.

***What is lymphoedema?***

The lymphatic system works in tandem with the body's circulatory system to drain water, cellular debris, toxins, bacteria, dead, dying or mutant cells and enzymes, and other macromolecules from the space around the body's cells. The lymphatic system filters this lymph fluid and returns some of the filtered fluid to the circulatory system. When the lymphatic system is compromised, the lymph fluid accumulates in the space around the cells of the body. The resultant swelling is known as lymphoedema. Left untreated, lymphoedema leads to chronic inflammation, hardening of the skin that, in turn, results in further lymph vessel damage and distortion of the shape of the affected body part. Lymphoedema, for the most part affects the legs, arms, trunk, genitals, head or neck. Lymphoedema is a condition that develops slowly and once it is present it is usually progressive. People can be born with abnormalities of the lymphatic system. This type of lymphoedema is known as primary lymphoedema. Depending on how severe the condition is, swelling can be present at birth or may develop later in life. Secondary lymphoedema occurs from damage to the lymphatic system, commonly from cancer and its treatment but also from trauma to the skin such as from burns, infections or vascular issues. Lymphoedema after breast cancer has been studied the most, but lymphoedema can occur as a result of other cancers, including melanoma, gynaecologic cancer, head and neck cancer. The risk of developing lymphoedema does not diminish over time but is a lifelong risk.

Lymphoedema may produce significant physical and psychological morbidity. Increased limb size can interfere with mobility and affect body image. At least fifty percent of people living

with lymphoedema experience pain and discomfort.[1] Patients are also more susceptible to acute celluilitis which can result in frequent hospitalisation and long term dependency on antibiotics. Lack of treatment for lymphoedema can lead to increased swelling and pain, irreversible damage to the lymphatic system, recurrent infections, the inability to work and reduced psychological wellbeing and quality of life. Potential cost savings could be realised from more effective management of lymphoedema patients, particularly in relation to hospital admissions for cellulitis and septicaemia. A 2003 study[2] reports that over 80% of patients had taken time off work due to their lymphoedema, with an estimated mean time off work of 10.5 days for medical appointments. Overall, 9% stated that the lymphoedema affected their employment status, with 2% of patients having to change jobs because of their oedema and 8% having to give up work because of it.

***Treatment for lymphoedema***

Lymphoedema has no cure but can be successfully managed when properly diagnosed and treated. Early diagnosis is important since treatment is most effective when lymphoedema is diagnosed at the earliest stage. Every patient with lymphoedema should have access to standardised, effective, multi-disciplinary treatment for the condition. These services should include regular reviews of the clinical circumstances of the condition, specialist decongestive manual therapy, compression garment fitting and supply, psychological support, diet and exercise guidance and education to support self-care. Access to these services should be on the basis of need and should not be determined by an individual's financial circumstances.

***Lymphoedema in Ireland***

*Lymphoedema Ireland* has estimated that approximately 15,000 people are living with lymphoedema in Ireland today, and this figure is set to increase considerably as result of the predicted increase in cancer survival, the aging population and growing levels of obesity. Section 1 of this document sets out in more detail the background to these figures.

A detailed study was undertaken by researchers from the School of Nursing in Dublin City University in association with the Irish Cancer Society in 2010. The study – "Living with Lymphoedema in Ireland: Patient and Service Provider Perspectives", highlighted the dearth of research in lymphoedema as well as the inadequate, disjointed, and under resourced services in Ireland. The study documented that patients must navigate the health system themselves; they must seek out their own care, often having to pay privately for treatment just to be able to continue with daily living. In many cases, people with lymphoedema have to travel overseas to access treatment to meet their needs. This places a massive strain on patients, many of whom are already dealing with issues relating to cancer survival or other issues related to complex health conditions. The study also highlighted that those practitioners working in the health system and trying their best to assist patients, believe that the services are inadequate; that

[1] Moffatt CJ, Franks PJ, Doherty DC, Williams AF, Badger C, Jeffs E, Bosanquet N, Mortimer PS. Lymphoedema: an underestimated health problem. Quarterly Journal of Medicine 2003: 96:731-738
[2] Moffatt et al 2003

they themselves are not trained sufficiently and most significantly, and ultimately that patients' needs are not being met.

*Lymphoedema Ireland* is concerned about the often differing experience of our members who have a medical card compared to those who don't, and between those with primary and secondary lymphoedema. The 2010 study was clear in concluding that inequalities exist between people with lymphoedema. Participants in the study with primary and non-cancer related secondary lymphoedema scored significantly lower in physical health, psychological and quality of life measures – often waiting much longer for lymphoedema diagnosis and any opportunity for treatment. This unequal access to treatment and benefits is hugely significant. The cost of procuring treatment privately is prohibitive, so too is the cost of custom-fit compression garments. Our members report that most private insurance companies have limited cover for manual therapy with most not sufficiently covering the cost of intensive treatment. A single hour of Manual Lymph Drainage (MLD) massage with a private practitioner costs our members minimum €60. It would not be unusual for a person living with lymphoedema to require, in their clinical best interests, twice weekly MLD sessions. Compression garments range in costs depending on an individual's needs. Average costs are between €600 and €3,000 per year per patient. As a result of these high costs, many of our members are not receiving the treatment that they require and their conditions are deteriorating. Further details on Living with Lymphoedema in Ireland is set out in Section 2 of this document.

***Lymphoedema Ireland's appeal to the Expert Panel and the HSE***

Acknowledging the competition for resources and the demands on the health system at this time, ***Lymphoedema Ireland*** **recommends that patients with lymphoedema are granted a medical card on the basis of their medical and social service needs arising from their condition.** This should provide patients at a minimum with access to multi-disciplinary services, necessary medical supplies including bandages and specially fitted compression garments, donning and doffing aids, medication including pain medication and prophylactic antibiotics and mobility aids where necessary.

This however, is in acknowledgement of the **extreme lack of adequate services and supports for people with the condition currently.**

*Lymphoedema Ireland* is aware that the HSE has recently conducted an internal survey of services available to people with lymphoedema. *Lymphoedema Ireland* is confident that this has demonstrated the ad hoc nature of service provision, as well as the lack of a standardised approach to access and treatment. *Lymphoedema Ireland* is calling on the HSE to respond to the findings of this survey and prepare a plan for the development of services for people with lymphoedema. This is in recognition that the incidence of lymphoedema in Ireland is set to increase. This planning should be undertaken in consultation with practitioners and patients and should be predicated on the adoption of international best practice standards for treatment (*International Consensus: Best Practice for the Management of Lymphoedema,*

International Lymphoedema Framework). *Lymphoedema Ireland* has set out a detailed overview of what such a service would comprise and this is presented in Section 3.

*Lymphoedema Ireland* and our members are more than happy to discuss any aspect of this submission and our findings with officials in the HSE and members of the Expert Group.

## Structure of this submission:

Section 1- How many people live with lymphoedema in Ireland? ..... 7

Section 2 - Living with Lymphoedema in Ireland ..... 9

Section 3 - Lymphoedema Ireland's vision for an effective and patient-centred service for people living with lymphoedema in Ireland ..... 14

Section 4 - Impact of good quality services for people living with lymphoedema in Ireland ..... 20

# Section 1

## How many people live with lymphoedema in Ireland?

**There are a growing number of people living with lymphoedema who will require on-going treatment, surgical supplies and multi-disciplinary support. The estimated incidence and prevalence is not reflected in the number of people receiving services. There is a diagnosis and treatment deficit in Ireland giving a substantial unmet need for this group of people.**

***Current estimates***

The prevalence of lymphoedema found in a South West London 2003 study was 1.33 per 1,000 population, with the figure increasing to 5.4 per 1,000 population in the over 65 years[3]. Other studies have shown similar rates, up to around 2 per 1,000.

At birth, about one person in 6,000 will develop primary lymphoedema[4]. However, these figures are likely to underestimate the true prevalence given the lack of awareness and the under diagnosis of the condition.

The incidence of secondary lymphoedema in Ireland following treatment for cancer treatment is unknown. Thanks to advances in the early detection and treatment of cancer, over 60% of people in Ireland survive for five years or longer after a cancer diagnosis and go on to live a normal and healthy life. Up to 100,000 people are now living with cancer in Ireland and there is a growing need to understand better the life changing implications a cancer diagnosis brings. Lymphoedema incidence estimates for various cancers range between 5% and 66%. Taken together conservative estimates suggest that 20% of breast, genitourinary, gynaecological, or melanoma survivors will experience secondary lymphoedema (National Breast and Ovarian Cancer Centre, Australia 2010).

*Lymphoedema Ireland* has examined the National Cancer Register and examined the prevalence of breast, prostate, melanoma and gynaecological and genitourinary cancers. Taking the conservative estimate of a rate of 20%, a minimum of 1,263 people develop lymphoedema following treatment for cancer each year. These people will live with lymphoedema, along with the other consequences of cancer treatment, for the rest of their lives. Examining the number of survivors at 15 years, it is estimated that 10,678 cancer survivors are living with secondary lymphoedema following a cancer diagnosis.

If these figures for secondary lymphoedema following cancer treatment are taken together with the estimate relating to primary lymphoedema, *Lymphoedema Ireland* estimates that at an absolute minimum, 12,000[5] people are living with lymphoedema in Ireland. This estimate does

[3] Lymphoedema: an underestimated health problem. C.J. Moffatt, P.J. Franks, D.C. Doherty, A.F. Williams, C. Badger, E. Jeffs, N. Bosanquet and P.S. Mortimer, J. Med 2003 96:731-738

[4] International Consensus: Best Practice for the Management of Lymphoedema, Lymphoedema Framework

[5] Based on census 2011 population figures of 4,588,252

not take account of secondary lymphoedema developed from a trauma not related to cancer treatment, or those people living with lymphoedema in the community without a diagnosis. This figure is far in excess of the number of people reported to be living with either multiple sclerosis or Parkinson's disease in Ireland today.

Cancer cases in Ireland are expected to rise to 42,000 annually by 2020. The number of people aged over 65 in Ireland will double over the next 30 years. While many people will enjoy good health, the number of new cancer cases will rise steadily, to reflect the ageing population. More people are surviving and going on to have healthy lives after cancer. The rising incidence of cancer is coupled with significant improvements in diagnosis and treatment. More people are living longer and the number of cancer survivors continues to grow. Many, however, do not receive the longer term support they require. International research and policy statements have clearly identified what constitutes effective post-treatment care and support. In Ireland there are still significant gaps. It makes statistical sense that more people will develop lymphoedema in the coming years, and more people will be requiring services in order to live healthy and fulfilling lives. This naturally requires consideration of the future of service provision and the need to examine risk identification, early detection and the sustainable provision of suitable treatment in order to manage the demands that these individuals will place on the health services as they seek to continue to live full active lives and contribute to society and the economy.

**The number of people at risk of developing lymphoedema as a result of treatment for cancer is likely to increase. More people are surviving cancer and living on with the effects of this treatment.**

Obesity contributes to the onset of lymphedema and often worsens the symptoms of already existing lymphedema. In a study conducted by researchers of the University of Missouri-Columbia[6], it was suggested that the risk of developing upper extremity lymphedema following breast cancer surgery was 40-60% higher in women with a body mass index (BMI) classified as overweight or obese, compared to women with normal weight. In their study, which included 193 breast cancer survivors, researchers also report that the risk of lymphedema is especially high in overweight or obese women who experience cancer treatment involving the dominant side, or experience post-operative swelling.

Excessive weight, especially morbid obesity, may also contribute to the onset of primary and secondary lymphedema involving the lower extremities. According to recent research, ten years ago, one in eight Irish men were categorised that figure is now officially put at one in four. In the same period, obesity in women has risen from 13% to 21%. 61% of adults and more concerning, 22% of 5-12 year olds are overweight or obese. Therefore it makes statistical sense that there is a growing cohort of people in Ireland who are at risk of developing lymphoedema.

[6] published in 2008 in the Journal of Lymphoedema Vol.3, No.2

## Section 2

## Living with Lymphoedema in Ireland

**Lymphoedema is a chronic, incurable and debilitating condition which can have series impact on the quality of life for people with the condition. If not treated effectively, consequences include long term disability, serious infection, reduced quality of life, emotional problems and problems at work.**

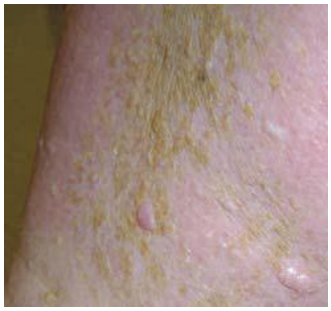
The implications of living with lymphoedema are multi-faceted – financial (e.g. cost of treatment, compression garments and bandaging), physical (e.g, pain and cellulitis), social (e.g. activity levels, socialising), emotional (e.g. sadness, frustration), and psychological (e.g. poor self-image, self-confidence, depression, isolation). Accessing treatment is one of the key causes of anxiety and frustration among people living with lymphoedema in Ireland.

Many of our members have so much difficulty accessing appropriate treatment for their condition that they resort to travelling overseas to access care there. The HSE has until recently (2012) routinely approved patients to travel to specialist lymphoedema clinics in Germany, Austria and the UK to access intensive treatment as part of the State's obligations under the EU Travel Abroad Scheme (E112 Directive). These patients have been fully supported by their treating consultants who themselves, have determined that suitable treatment for their patients is not available in Ireland. By approving such applications, the HSE has acknowledged that comparable treatment is not available in Ireland. However, more recently, *Lymphoedema Ireland* has been contacted by numerous people with lymphoedema who have been refused access to these specialist in-patient centres despite such treatment continuing to be unavailable in Ireland. As a result, these consultants and medics are left without any referral options and without the ability to arrange suitable treatment for their patients. Consequently, the medical condition of these patients is deteriorating and they are at increased risk of complications of lymphoedema, including frequent and recurrent cellulitis infections as well as continuing deformity and decreasing mobility and independence.

The 2010 study *Living with Lymphoedema in Ireland: Patient and Service Provider Perspectives* is essential reading for any policy maker as it provides clear evidence of the difficulties and hardship faced by our members on a daily basis. Whilst the findings of the 2010 study are significant, it is worth cautioning that the majority of the patients who took part in the study were accessed through hospitals and services. As a result, people living with lymphoedema who were not receiving treatment were less likely to have taken part. Furthermore, whilst the study is less than five years old, it was a snapshot of service provision at that time. It is worth bearing in mind, the considerable financial and other resource constraints that have been placed on health services generally at this time. Likewise, the financial position of individuals, either living with or without lymphoedema has likely deteriorated in the period since. Nonetheless, the study is a very important step in documenting the experiences of service provision and living with lymphoedema in Ireland and validates *Lymphoedema Ireland*'s demand for an integrated,

equitable, standardised and multi-disciplinary service for people living with lymphoedema in Ireland.

**Services are under-resourced, overstretched and inequitable**

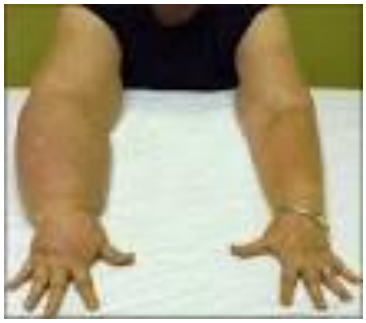


**Lack of knowledge about lymphoedema and its treatment amongst health care professionals and difficulty getting a diagnosis**

- Our members report that their GPs, often their oncology teams and/ or other medical professionals are unaware of the condition and do not appreciate the impact of the condition on people with lymphoedema and their families.
- Our members report that they have had difficulty getting a diagnosis. The 2010 study showed that patients with primary lymphoedema spent much longer waiting for a diagnosis when compared with patients with all other types of lymphoedema. Patients with primary lymphoedema waited on average 78.2 months for a diagnosis, patients with non-cancer-related secondary lymphoedema waited on average 20.6 months, and patients with cancer-related (but not breast-cancer-related) secondary lymphoedema waited an average of 8.2 months, while patients with breast-cancer related lymphoedema waited on average 4.8 months for a diagnosis.
- Only 42% of respondents indicated that they knew they were at-risk of developing lymphoedema. There was a highly significant association between patients who knew they were at-risk of developing lymphoedema and the type of lymphoedema they subsequently developed. While 52% of patients with breast-cancer-related secondary lymphoedema knew they were at-risk; only 24% of those with cancer-related (but not breast-cancer-related) lymphoedema; 7% of primary lymphoedema patients and just 5% of those with non-cancer-related secondary lymphoedema knew they were at-risk of developing the condition.
- Our members report the lack of information and advice for patients about the condition.
- Our members report that there are no clear referral pathways in order to access treatment. There is no identifiable way of getting treatment to meet their needs.

**Insufficient, inadequate and ad hoc provision of services**

- The limited and inadequate services that are available are mostly provided in large, public hospitals situated in counties with major towns and cities. The 2010 study found that practitioners' reported that on average their patients were required to travel 71km to access their lymphoedema services, with many having to travel far greater distances. Our members in rural arrears receive even poorer services.



- Our members report that there is no standardisation of care on a whole of service basis. The availability of treatment varies. Some offer bandaging and MLD, other instances only offer garment fitting. The 2010 study found that where

services are provided, only three quarters of the practitioners provided time-consuming treatments such as MLD, or CDT or compression garment fitting despite there being international consensus on the essential nature of these approaches in the effective management of lymphoedema.

- The 2010 study found that when practitioners were asked to rate the standard of care received by patients with different types of lymphoedema on a scale from 1- 'very low' to 5 - 'very high'. More than one out of every two people (58%) rated the standard of care for people with primary lymphoedema as very low or low; two out of every three people (68%) rated the standard of care for people with non-cancer related secondary lymphoedema as very low or low; 43% rated the standard of care as low or very low for people with cancer (non-breast cancer related) lymphoedema; and 23% rated the standard of care for BC related lymphoedema as very low or low.
- Our members experience is that there is no integration of services, i.e. social work, psychologists, despite the fact that there is international consensus of the psychosocial difficulties that are associated with lymphoedema. None of the practitioner respondents in the 2010 study reported working in a service that has a social worker, psychologist, or psychiatrist employed in the treatment of lymphoedema patients, despite the fact that psychosocial and mental health difficulties can be associated with lymphoedema.

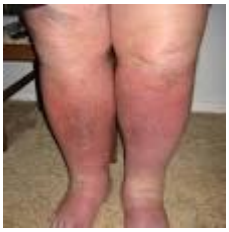
- Our members experience demonstrates an ineffective use of resources presently – trained physios working in physio units that are not treating lymphoedema patients.
- Only 78% of practitioner respondents in the 2010 study had received specialised training from one of the lymphoedema schools, which is deemed essential for the appropriate treatment of lymphoedema. Just over half of practitioners who personally treat lymphoedema patients had received training by compression garment providers on fitting garments. Approximately half of respondents reported keeping up to date with developments through journals, magazines, conferences or workshops. 94% of respondents reported insufficient opportunities for professional development.

**Poor garment provision and support**

- The international consensus of lymphoedema practitioners is that an individual with one lymphoedematous limb should receive a minimum of two garments every three to six months or even more frequently if the patient is active (MEP, 2006)[7]. This permits the washing of one garment while another is worn and ensures that the level of compression provided by the garment is optimal. Our members experience demonstrates an inconsistent availability of garments and bandages - medical card patients have reported long delays in HSE approval procedure; some patients receive bandages as medical holders, others receiving bandages through the Drugs Payment Scheme, others not.

[7] Medical Education Partnership (MEP). (2006). International Consensus Best Practice for the Management of Lymphoedema. Medical Education Partnership LTD.: London, UK

- A high proportion of the patient respondents (70%) in the 2010 study, did not receive the minimum amount of compression garments from their main lymphoedema service.



- 57% of respondents reported replacing their garments the recommended two-three times a year. 17% indicated that the cost of garments affected whether they replaced them. 9% of respondents who currently use garments reported having difficulties getting re-measured because practitioners are too busy to measure patients; lymphoedema services have been discontinued, and patients do not know where to go to be re-measured.
- 61% of those who currently used garments have a medical card and of those 18% indicated that having a medical card slowed down the delivery of their compression garments.

- Despite being a long term chronic condition, the *Long term Illness* Scheme is not available to people with lymphoedema.
- Our members report that the cost of (medically prescribed) and essential compression garments are not included on the *Drugs Payment Scheme*. As a result, non-medical card holders must self-fund the cost of compression garments every six months. Our members report the cost of these garments being between €250 and €3,000; these garments must be replaced every six months. However, some of our members have reported that they have been successful in having the cost of their garments met within the Scheme.
- Our members report that some private health insurance companies only refund the partial cost of some compression garments. Patients must pay for the garments upfront and cover the cost of the difference.

**Cost of treatment privately**

- The absence of a good quality, integrated services that meet the needs of patients, places a significant financial burden on patients in order to receive adequate treatment and supplies to effectively manage their symptoms.
- Our members report that most private insurance companies have limited cover for manual therapy with most not sufficiently covering the cost of intensive treatment.
- A single hour of Manual Lymph Drainage (MLD) massage with a private practitioner costs our members minimum €60. It would not be unusual for a person living with lymphoedema to require, in their clinical best interests, twice weekly MLD sessions.
- These costs are in addition to the additional financial burden that some of our members experience arising from their cancer diagnosis and treatment.

**Personal impact of living with lymphoedema**

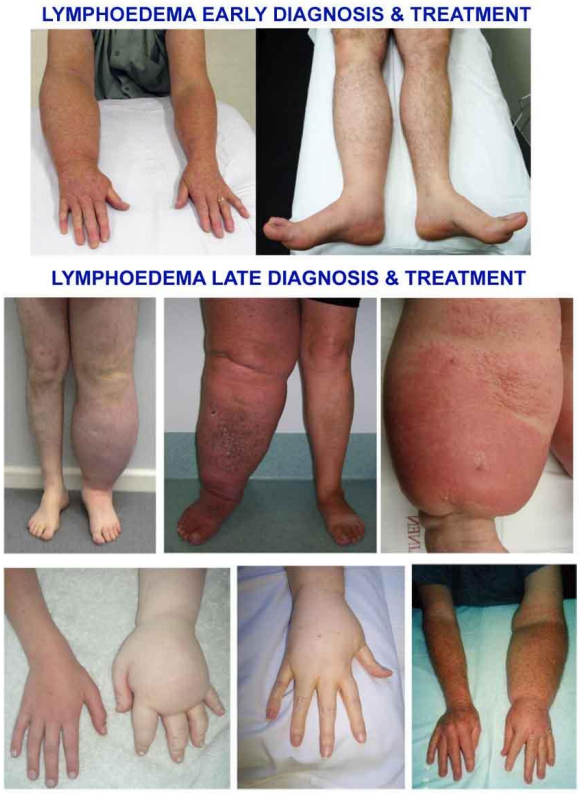
- Many of our members feel isolated, vulnerable and unsupported by their health care professionals.

- The results of the 2010 study suggest that there are huge variations in the impact of lymphoedema and that appropriate levels of treatment and the provision of support groups and counselling may offer the potential of lessening the consequences of lymphoedema for those who feel it most keenly.
- At least 30% of respondents experienced limitation across each of the specified aspects of their daily lives. The limitations that lymphoedema imposes on patients' lives were more keenly felt with regard to their ability to perform indoor (77.7%) and outdoor (80.9%) chores, wear clothes/shoes (77.8%), and go on holidays (68.1%).
- Participants with non-cancer-related secondary lymphoedema experienced greater limitation than participants with other types of lymphoedema in walking, swimming, performing other sports, performing outdoor chores, taking care of children, buying clothes/shoes, wearing clothes/shoes, socialising, sexual activity, sleeping, and going on holidays.
- 29% of all respondents reported that they had experienced a bout of cellulitis, an infection in the layers of the skin commonly associated with lymphoedema. On average respondents had been hospitalised for the treatment of their cellulitis twice. However the large range suggests that cellulitis can have a significant impact on some patients' lives.
- Participants reported just how distressing the condition is. In particular, many reported that it was difficult to deal with the diagnosis following their cancer diagnosis and treatment resulting in an incapacity to process their susceptibility to developing lymphoedema; lymphoedema as a constant reminder of cancer treatment; being required to adapt to a 'new body'; distress in response to the reactions of others; and fears for an uncertain future.

## Section 3

## Lymphoedema Ireland's vision for an effective and patient-centred service for people living with lymphoedema in Ireland

***Lymphoedema Ireland*** **demands an integrated, equitable, standardised and multi-disciplinary service for people living with lymphoedema in Ireland. The critical services that people with lymphoedema require are not sophisticated, innovative or involve high-cost drugs. The therapies are tried and their success proven. Individuals can manage their own condition with the correct support of health-care professionals.**




The two main components of a comprehensive service for people with lymphoedema in Ireland should include clinical intervention, in accordance with international best practice to manage the condition, and an awareness among health and social care workers, patients, carers and the public of the condition. The overarching aims should be to improve the quality of life and enable individuals with the condition to function as independently as possible.

Appropriate treatment should be available for people with all types of lymphoedema, primary and secondary, cancer and non-cancer related lymphoedema. Drawing on international experience, the hub and spoke model of service delivery is recommended. This involves intensive treatment bring provided in specialised clinics by a multi-disciplinary team and maintenance of the condition would be delivered in community services. These lymphoedema services should form a network liaising with each other, working from these standard protocols.

To assist in adapting to living with lymphoedema and self management of the condition, individual and group psychological support should be promoted and be made more readily available.

Lymphoedema Ireland is aware that this approach may require a dedicated funding stream and a lead clinician to be tasked with rolling out such a framework.

Key aspects of a comprehensive lymphoedema service include:

1. **People at risk of lymphoedema should be identified early during routine assessment, monitoring and taught how to avoid developing the condition.**

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 minimise the severity of lymphoedema, reduce frequency of complications and lessen the need for complex treatment. Studies have shown that a delayed diagnosis is a direct result of a lack of awareness of the condition among health professionals and multi-disciplinary teams. A wide range of clinicians come into contact regularly with and manage issues related to lymphoedema within the Irish health system. 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 comprehensively.

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[8]. 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;

[8] Moffatt et al, 2003

- Recurrent cellulitius

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, as well as -

- Immobility
- Recurrent cellulitis
- Trauma to the skin
- Wound healing problems
- Insect bites
- Sunburn
- Fungal infections, especially between toes
- Poor hygiene.

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.[9]

**2. Patients and carers should be offered information about lymphoedema and how to access treatment.**

Patients at risk of lymphoedema and their carers need to know what lymphoedema is; why the patient is at risk; how to maintain good health and how to minimise the risk of developing lymphoedema; early signs, and who to contact if swelling develops. Key strategies for maintaining the integrity of skin, preventing injury or infection and enhancing lymphatic system functioning through physical activity and breathing exercises is critical. Prevention and early diagnosis of cellulitis to which people with lymphatic impairment are vulnerable is important as described by the British Lymphology Society/ Lymphoedema Support Network Consensus Guidelines (2013).

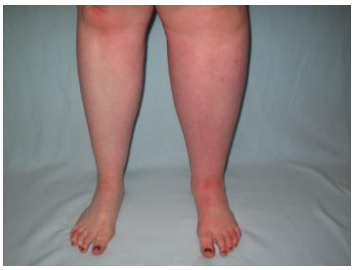
**3. An accurate assessment is essential for the appropriate treatment of lymphoedema. This should involve medical as well as other specialist investigations, e.g. vascular,**

[9] **SMASAC Short Life Working Group on Lymphoedema - Lymphoedema Care in Scotland, Achieving Equity and Quality;** November 22, 2013

**dermatological, pain, or psychological, that takes account of the individual needs of the person. Diagnosis should be made in accordance with accepted guidelines by qualified practitioners.**

The diagnosis of lymphoedema should be based on clinical history, physical examination and confirmation of diagnosis by specific tests, including lymphoscintigraphy where appropriate[10]. In suspected primary lymphoedema, specialist investigations are particularly important. The effect of chronic lymphoedema on the individual's body image needs to be considered; as such changes can have a negative impact on self-esteem. Limb swelling can restrict the patient's choice of clothing and footwear, which may contribute to relationship difficulties and depression. Furthermore, lymphoedema can result in functional impairment, reduced self-esteem, distorted body image, depression, anxiety, and problems with sexual, family and social relationships. Assessment should take account of the psychological health of the individual.

4. **Patients should receive a coordinated package of care and information appropriate to their needs. This should include access to a medical card on medical grounds and should not be related to the individual's financial circumstances.**



The aims of treatment for lymphoedema should be 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.

This should include access to psychological support, social supports to assist with day to day living, dietary and other appropriate treatments. The intention of such treatment should be to support the individual in managing their own condition and to maximise their quality of life.

5. **Services should be based on international standards of best practice and clinical guidelines** (e.g. *CREST Guidelines for the Diagnosis, Assessment and Management of*

[10] Lymphoedema Framework (2006) Best practice for the Management of Lymphoedema. International consensus. MEP Ltd., London, UK.

*Lymphedema*; *Best Practice for the Management of Lymphoedema, International Lymphoedema Framework*).

This treatment should include the provision of high quality clinical care for people with cellulitis. Agreed protocols for the rapid and effective treatment of cellulitis, including prevention of recurrent episodes, should be implemented and monitored by healthcare professionals who have completed recognised training in this subject.

6. **Treatment should be provided in a location that is accessible to the patient in a centre that has sufficient expertise and experience to meet the patient's needs.**

Appropriate treatment should be available for people with all types of lymphoedema, primary and secondary, and cancer and non-cancer related lymphoedema and should be determined by the individual needs of the patient. Drawing on international experience, the 'hub and spoke' model of service delivery is recommended. This involves intensive treatment bring provided in specialised clinics by a multi-disciplinary team whereas maintenance of the condition could be delivered in satellite or community based services. Ideally, these lymphoedema services would form a network liaising with each other, working from these standard protocols. To assist in adapting to living with lymphoedema and self management of the condition, individual and group psychological support should be promoted and be made more readily available.

7. **Treatment should be adapted to the individual patients needs and should be based on practice which has a holistic, multi-disciplinary approach which includes:**
    - Swelling reduction and maintenance through a combination of compression, bandaging (multi-layered inelastic bandaging ) and exercise and movement, manual lymphatic drainage massage (MLD)
    - Skin care
    - Exercise
    - Weight management
    - Self-care education
    - Risk reduction
    - Pain and psychological management

    The exact course of treatment should be determined by the affect area, stage, severity and complexity of the individual's needs.

8. **Complex Decongestive Therapy (CDT)** is the current international standard of care for managing lymphoedema and is the combination of skin care, exercise, MLD and multi-layered bandaging. CDT has been shown to be effective in large numbers of case studies demonstrating limb reductions of 50-70% or more, improved appearance of the limb, reduced symptoms, improved quality of life and few infections after treatment. Even people with progressive lymphoedema for more than 30 years or more before starting CDT have been shown to respond.

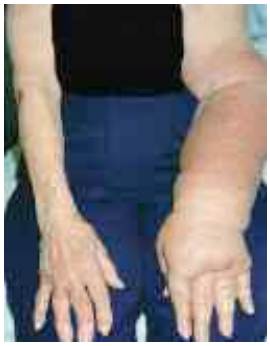
9. **Intensive treatment should be, in accordance with international best practice, undertaken for a period determined by the unique requirements of the patient. During this time treatment should be evaluated continuously and appropriate alterations made according to patient need.**

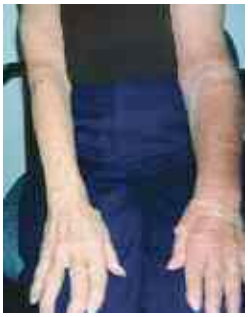
10. **Correctly fitted compression garments should be prescribed appropriately for patients with lymphoedema and fitted by trained professionals. The cost of these garments should be regarded as approved medical supplies and should be fully covered as part of the medical card system.**

The main use of compression garments is in the long-term management of lymphoedema usually following a period of intensive therapy. Some patients wear garments during waking hours only, for exercise only, or up to 24 hours per day. Accurate measurement is critically important to achieve the correct fit and appropriate training is essential. Agreed protocols should be developed for the assessment and provision of compression garments for people with lymphoedema, or those at risk of lymphoedema. Garments are an essential component of the management of lymphoedema and patients should have full access to appropriately fitted garments. Garments should be replaced every three to six months, or when they begin to lose elasticity. Young or very active patients may require more frequent garment replacement.

11. **Patient-appropriate surgical treatment should be available and offered to patients in accordance with international best practice and developing guidance. Treatment options should include – surgical reduction, procedures to bypass lymphatic obstructions, and liposuction.**

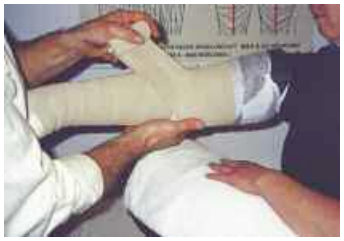
12. **Patients should have a structured and regular follow-up and check-up routine with on-going support and assistance. Patients should be supported in taking control of their own health and the daily maintenance of the condition.**





## Section 4

# Impact of good quality services for people living with lymphoedema in Ireland


Whilst lymphoedema is not curable, it can be alleviated with appropriate management. A study of over 700 chronic oedema/ lymphoedema patients in Scotland found that 97.5% of those who received specialist care had their swelling controlled, compared to 80% of those treated in non-specialist services[11].

A lack of recognition of lymphoedema symptoms or inadequate treatment may lead to specific complications such as recurrent cellulitis and other infections that require hospital admission incurring considerable costs. Lack of treatment for lymphoedema can lead to increased swelling and pain, irreversible damage to the lymphatic system, recurrent infections, the inability to work and reduced psychological wellbeing and quality of life. Potential cost savings could be realised from more effective management of lymphoedema patients, particularly in relation to hospital admissions for cellulitis and septicaemia. For example, one English survey, reported in the Quarterly Journal of Medicine[12] records that 29% of lymphoedema patients had experienced at least one acute infection in the affected area. Of those experiencing acute infections, 27% were admitted for intravenous antibiotics. Over the duration of their oedema, 15% had experienced at least one hospital admission for their oedema. The mean length of hospital stay was 12 days, with an estimated cost of hospital stay of £2,300[13]. The NHS Institute for Innovation and Improvement noted that there were 45,522 inpatient admissions for cellulitis in 2003–2004, costing the NHS £87m[14]. Similar estimations are not available in Ireland however

The NHS has recently estimates it saves an estimated £100 in reduced hospital admissions for every £1 spent on lymphoedema treatments that limit swelling and prevent damage and infection.[15]

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[11] Lymphoedema: Service Provision and Needs in Scotland. Margaret C Sneddon University of Glasgow funded by Macmillan Cancer Support UK

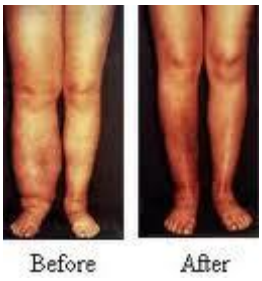
[12] Moffatt CJ, Franks PJ, Doherty DC, Williams AF, Badger C, Jeffs E, Bosanquet N, Mortimer PS. Lymphoedema: an underestimated health problem. Quarterly Journal of Medicine 2003: 96:731-738

[13] Netten A, Rees T, Harrison G. Unit costs of health and social care 2001. PSSRU, University of Canterbury, Canterbury 2001

[14] Firas A & Cox N (2009) Journal of Lymphoedema. Cellulitis and lymphoedema: a vicious cycle

[15] Cancer And Palliative Care Rehabilitation: A review of the evidence (NCAT 2012); Cancer Rehabilitation; making excellent cancer care possible (NCAT 2013); Macmillan's Routes from Diagnosis

In addition, more effective management of lymphoedema patients should reduce the input of pain management, tissue viability and skin breakdown.




Appropriately managed patients should also have a better quality of life, thus increasing ability to work and reducing the level of associated disability benefits.

## Who are *Lymphoedema Ireland*?

*Lymphoedema Ireland* was founded in 1995. Our volunteer patient-led national network offers support, help and information to anyone in Ireland affected with lymphoedema. Membership is open to anyone who suffers from Lymphoedema, their family and friends and those with an interest in furthering the aims of the network. Our members are of all ages, come from all parts of the country, and have experienced a variety of health issues. However, members have a shared experience of living with lymphoedema and the insufficient services that are available to people with this chronic condition.

***Our Aims and Objectives are:***

- To campaign for improved services and standards of care in Ireland for people with lymphoedema.
- To publicise the lack of diagnosis, services, treatment and support for people with lymphoedema.
- To provide support and information to such persons and their families.
- To promote a high standard of information and promote self-help.
- To advance the education of the public on the subject of Lymphoedema.
- To maintain contact with healthcare professionals working in Lymphoedema management.
- To promote better awareness of lymphoedema as a major health condition to local health authorities, healthcare professionals and politicians.

The organisation is led from a strategic perspective by a committee of members that includes patients, practitioners and medical professionals. The work of the organisation is supported by our medical patron Dr. Mary-Paula Colgan.

Lymphoedema
IRELAND

## Contact Us

For further information or to access the helpline please contact:

*Lymphoedema Ireland*
*c/o The Irish Cancer Society*
*43/45 Northumberland Road*
*Dublin 4.*

**Telephone** **087 6934 964**

**Freefone helpline:** **1800 200 700**

Email: info@lymphireland.com

Website: www.lymphireland.com