

Lipedema Directive 2014

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**Patient version**



## Colophon

### Lipedema directive, patient version, 2014<sup>®</sup>

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The content of this brochure is based on the 2014 version of the multidisciplinary, evidence-based medical lipedema directive.

This brochure has been written by the NVDV in cooperation with NLNet

The NVDV is a professional association of Dutch dermatologists and is not a patient association. The purpose of the association is the advancement of the study of skin diseases. In addition to its scientific activities and a variety of organizational missions, such as representing the interests of its members, the NVDV also has a public aim, which is to inform people about the occurrence and the history of skin conditions. This information is dispensed through the distribution of leaflets as well as online publications.

Translation into English has been made possible by generous grants from the NVDV (Dutch Society for Dermatology and Venereology), Haddenham Healthcare UK, the FDRS (Fat Disorders Research Foundation, USA) and the SLCN (Dutch Foundation for lympho-vascular medicine).

NLNet is the patient organization for people with lymphedema and lipedema. The Dutch Foundation Network for Lymphedema and Lipedema (*Stichting Nederlands Netwerk voor Lymfoedeem en lipoedeem* or NLNET) aims to be an independent platform to provide (scientific) knowledge, domestic and international directives, and lymphedema and information about experiences with lipedema to those who have to address lymphologic conditions, particularly lymphedema and lipedema. The informational materials provided by the organization are aimed both at patients and patient organizations, as well as care providers. By drawing attention to these conditions, the quality of and access to care for this group of patients can improve. These groups also represent patient interests; for NLNet, the patient is central. The principle is respect for patients' needs and. NLNet endeavors to accomplish this goal by developing and maintaining an internet platform, publishing a magazine ('Lymfologica'), organizing a biannual patient conference, and facilitating regional support groups and many other activities.

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## LIPEDEMA DIRECTIVE, PATIENT VERSION

You have (a risk of) lipoedema and how to proceed from here.

### Introduction

The Lipedema Directive can be found on the websites of all the associations involved in the production of the directive, primarily the Dutch Association for Dermatology and Venereology (*Nederlandse Vereniging voor Dermatologie en Venereologie*, or NVDV). Other medical professionals are involved in the prevention, diagnosis, and treatment of lipedema, including (general and vascular) surgeons, plastic surgeons and rehabilitation specialists. Many allied health and nursing professionals are also involved in this directive, such as (edema) physiotherapists, skin therapists, orthopedists and healthcare providers measuring garments, as well as the patient organizations LIPV and NLNet. Representatives of these organizations have cooperated in creating this directive and are collectively responsible for its maintenance; the NVDV is the main driving force behind the directive and is responsible for supervising the guideline development process and its content.

Because lipedema is a chronic condition, the chronic care model should be evaluated for its suitability in approaching patients with lipedema. This model is based on the assumption that people with a chronic condition will only change their behavior when they are given a leading role and responsibility. The concept of 'self-management' holds a central position in this model. Self-management means that people are able to deal well with their chronic condition and its consequences. Many initiatives may be able to stimulate self-management, but such initiatives are not yet widespread. Social assistance with self-management requires aid workers to play a different role, similar to that of a coach. The medical care of patients with lipedema healthcare should be adjusted to better fit these roles.

This patient version is derived from the lipedema directive that was established under responsibility of the working group.

### Directive working group procedure

At the start of the directive's development, all participating associations were asked to reflect on their everyday experiences regarding the most important obstacles to improving healthcare. Based on the identified stumbling blocks, several reference questions were selected by the members of the working group for directional literary research:

- How and when is lipedema defined?
- Which aspects should be ascertained or excluded from adequate (early) diagnostics and follow-up of lipedema? How can the diagnostic process be followed and evaluated?
- What should the treatment of lipedema patients include?
- What is the role of patient organizations in assisting patients with lipedema?

In this patient version, all of these questions are briefly discussed.

## 1. How and when is lipedema defined?

### 1.1 Irregularly distributed fat tissue

Lipedema is a condition in which fat tissue is irregularly distributed over the body. Localized, symmetrical accumulations of fat develop (on both sides of the body) on the hips, buttocks, thighs, lower legs, inside of the knees or the arms. Lipedema develops during or shortly after puberty, but the condition can also develop during pregnancy or at a later age, during menopause. The condition almost exclusively affects women, and there are often multiple cases in families, yet the disease has not yet been proven to be inherited.

### 1.2 Other symptoms

Other important symptoms are:

- There is virtually an overall improvement of fat reduction with weight reduction, but the disproportionality persists
- Fat disappears in other places (face, breasts, trunk etc.), more easily by weight loss.
- Fat is present under the skin, around a section of the legs or arms ('blubber legs' or 'wobbly legs') and stops abruptly. In cases where the lower legs are affected, the fat deposits end abruptly above the ankles, resulting in a distinctive edge. It appears as if the ankles have been cuffed, causing the legs above to swell; this is therefore referred to as the 'cuff sign'.
- A similar pattern can be seen when the arms are affected; the fat deposits continue to the wrists, with slender hands below them.
- Ankles, feet, wrists and hands are of normal size.
- Lipedema in the legs is accompanied by a painful, heavy, fatigued sensation.
- The skin is sensitive to external pressure and is easily bruised.
- 'Orange peel skin' (cellulite) is common.
- There is often a notable difference of two to three clothing sizes between the upper and lower body.
- Some lipedema patients display a loss of muscle strength in the arms and legs. In many cases this coincides with increased body weight, which is peculiar, as one would expect an increase of muscle strength in such instances.

## 2. How is lipedema diagnosed?

Despite the aforementioned symptoms, which are fairly characteristic of the condition, it can still be hard to diagnose lipedema. It is important to perform a detailed examination of a patient with (suspected) lipedema, paying attention to several objectively measurable characteristics, such as:

- (Repeated) measurements of the circumference of the affected legs and arms (often referred to as the extremities);
- The body mass index (BMI), a measurement that standardizes weight in relation to height;
- The abdominal circumference and the relationship between the circumferences of the hip and waist (the hip/waist ratio);
- Determination of daily activity;
- Stemmer's sign (which can be negative in the early stages of disease), a test for lymphedema that involves pinching and pulling the skin between the second and third toes; if this is possible, there is no lymphedema;

In the later phases of lipedema, lymphedema can occur. By then, Stemmer's sign will no longer be useful as a diagnostic tool. Lipedema is not associated with abnormalities in blood tests; however, blood tests can be useful, as some patients have other medical conditions that could cause similar symptoms. A CT scan can be useful for diagnosing lipedema, if other diagnostic tests are inconclusive. If lymphedema is also suspected, quantitative lymphoscintigraphy can likewise be useful for demonstrating irregularities in the lymphatic system (see also Lymphedema Directive 2013, and its patient version).

Difficulties with posture and movement are prevalent in lipedema. Many patients describe fatigue in the legs and the entire body, decreased endurance, and loss of muscle strength in the legs (which can cause difficulty climbing stairs, getting up out of deep chairs or cycling). Orthopedic problems are often found in lipedema patients, mostly manifesting in the knees or, less frequently, in the ankles. Many patients have balance difficulties that are due to stance deformities such as increased valgus stance and flat or spread feet, among other problems. Stance in this context is described as the physical capacity (strength and speed) of the body to maintain balance and involves light pressure and the reaction thereto.

It is important to make a distinction between pain resulting from stance deformities and pain caused by lipedematous tissue around the knees. The latter is often mistakenly attributed to problems in the knee joints. The walking pattern can be disrupted by stance deformities or hindered by enlarged fat deposits.

Problems related to lipedema can decrease participation in society and in everyday functioning (work, hobby, or sport), and the patient may have persistently worsening symptoms. Generally, a reduction in the physical activity level is seen in most patients with lipedema.

It is difficult to predict the clinical course of lipedema. In some patients, the symptoms remain minor and stable over a longer period of time, while others can deteriorate rapidly.

Both in the diagnostic phase and in the treatment phase, it is important to recognize and treat both physical and psychosocial complaints.

### 3. What does the treatment of lipedema and care for lipedema patients consist of?

#### 3.1 Conservative (non-surgical) treatment

Presently, no treatments are available to cure lipedema. Instead, the aims of the treatment are:

- Decreasing symptoms;
- Improving physical activity levels;
- Preventing worsening lipedema;
- Preventing additional symptoms, such as the accumulation of fat and the loss of physical endurance;
- Addressing additional fluid retention (sometimes caused by an additional lymphatic drainage disorder) and varicose veins, and gaining an understanding of the condition and decreased physical mobility;

The treatment is based on a number of core principles:

- A healthy lifestyle;
- Maintenance of existing functions, improving activity, and reconditioning. The Dutch Norm for Healthy Exercise (*Nederlandse Norm Gezond Bewegen* or NNGB) offers some guidance;
- Improving muscle strength, particularly the calf muscles, as increased exercise will stimulate the lymphatic and vascular pump in the calves;
- Pressure therapy, such as therapeutic hosiery (compression stockings), that can increase the effects of muscle movement and may prevent edema;
- Dietary measures, including determining the food intake in relation to the use of calories (the so-called caloric balance);
- Psychological guidance.
- Manual lymphatic drainage is not helpful to patients suffering only from lipedema;

#### 3.2 Surgical treatment

As a last resort, liposuction (also called liposculpture) can be performed. During this surgery, fat tissue is removed by means of a liposuction device, tumescent anesthesia (a local anesthetic technique in which a large amount of fluid is injected), and the use of vibrating cannulas.

Liposuction restores functionality, lessens (hyper) sensitivity and swelling, significantly improving physical appearance and thereby the quality of life. Liposuction is a highly specialized treatment and is therefore only offered in a select number of centers to a select group of patients. Generally, patients are initially treated conservatively, and surgical treatment is offered only to carefully selected patients who have not improved sufficiently or want shape improvement.

Prior to surgery, it is important to receive permission from one's health insurance to have a clear overview of the financial consequences of surgery because in general these treatments are not reimbursed.

### 4. What is the role of patient organizations in the care of lipedema patients?

Patient organizations represent the best interests of patients. These organizations are a source of education and experience, provide opportunities for inter-patient contact and contribute positively to the quality of care for lipedema patients. Furthermore, they support group interests.

The Dutch Lymphoedema Network (NLNet), [www.lymfoedeem.nl](http://www.lymfoedeem.nl)) has been active in the Netherlands since 2006. The website is HON-certified, meaning that the information provided is reliable and transparent. This patient organization originally focused on patients with (a risk of) lymphedema and lipedema patients with a lymphatic component (see lymphedema directive, patient version). In recent years, NLNet has focused more on lipedema, as reflected by their recent name change to the Dutch Network for Lymphedema and Lipedema. The tax authorities recognize NLNet as a 'broad benefit intending society' ('*Algemeen Nut Beogende Instelling*'/ANBI), and it is exempted from legacy and heritage taxes. NLNet receives PGO subsidies to further support its efforts.

NLNet is embedded in the Dutch subscription bases for Dutch patient interest representation through *Ieder(in)*, the umbrella organization for people with physical and mental handicaps or chronic illnesses (*Ieder(in)*; [www.iederin.nl](http://www.iederin.nl)), the Dutch Patient Consumer Federation (*Nederlandse Patiënten Consumenten Federatie* or NPCF; [www.npcf.nl](http://www.npcf.nl)) and Skin Patients Netherlands (*Huidpatiënten Nederland* or HPN; [www.huidpatienten-nederland.nl](http://www.huidpatienten-nederland.nl)). NLNet has an informative website, organizes a biennial congress, and publishes a biannual magazine (*Lymphologica*). Support groups are organized twice yearly and support self-management courses taught by certified instructors in every region. Furthermore, patients are kept fully informed through social media (Facebook and Twitter) about the newest developments concerning lymphedema and lipedema.

The Lipedema Patient Association (*Lipoedema Patiënten Vereniging* or LIPV) has been active since April 2009 in the Netherlands. It was established because, at the time, no active patient organization existed specifically for lipedema patients. In addition to providing information and initiating patient-to-patient contact, the LIPV issues a minimum of six newsletters each year. They sponsor lipedema symposia and organize national and occasional regional meetings.

The Dutch Lipedema Day Foundation (*Stichting Nederlandse Lipoedeemdag*; <http://lipoedeemdag.nl>) organizes a biennial congress on lipedema.

In 2012, the book '*Onder de indruk van jou*' ('Impressed by you') was published on the initiative of NLNet; it features 28 portraits of people with lymphedema or lipedema and can be ordered at <http://www.onderdeindrukvanjou.nl/>.

In 2014, an educational film titled '*Lipoedeem – wij willen in beweging blijven*' ('Lipedema - we want to keep moving') was released on the collective initiative of lipedema patients, including the NLNet board member Barbara Boots NLNET board member. This film can be viewed on the NLNet website among others.



## 5. Informative websites

[www.nijsmellinghe.nl](http://www.nijsmellinghe.nl);

[www.lymfoedeem.nl](http://www.lymfoedeem.nl);

[www.lipoedeem.net](http://www.lipoedeem.net);

[www.huidarts.info](http://www.huidarts.info);

[www.lipoedeemdag.nl](http://www.lipoedeemdag.nl);

[www.lipv.nl](http://www.lipv.nl).