

# Lipoedema



Symptoms and Therapeutic Options

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# Preface

The board members of the Swiss Lipoedema Association drew up this information brochure in autumn 2016 in cooperation with various lipoedema specialists in Switzerland.

The brochure serves the Swiss Lipoedema Association as information material for the public and for patients and is meant to help specialists with the diagnoses.

In order to make reading easier the following shortcuts are being used:

CDP	Complete Decongested Therapy
IPC	Intermittent Pneumatic Compression Therapy
MLD	Manual Lymphatic Drainage
TLA	Tumescent Local Anaesthetics

At this point we would like to thank the following people for their professional support:

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# The illness Lipoedema

Lipoedema is a chronic and progressing illness, characterized by an abnormal distribution of fat cells showing a distinct disproportion between upper body and extremities. The disproportion is caused by symmetrically localised increase in subcutaneous fatty tissue in the upper or lower extremities. Almost only women are affected and lipoedema develops at times of hormonal changes (puberty, pregnancy, menopause etc.).

Lipoedema probably occurred rather early in human history. The characteristic changes in body shape were already shown 3500 years ago in a relief of the queen of Punt in the Egyptian temple Hatshepsut in Deir el-Bahari. A statue of the great goddess in the temple of Hal Tarxien in Malta aged 5000 years shows changes in the lower legs characteristic for lipoedema. The first scientific description however was made only in 1940.



Statue temple Hal Tarxien, Malta



Relief temple Hatshepsut, Egypt

There are various synonyms for this illness; they all contain the term fat (*lipo*, *adipos*) and the term pain (*algie*, *dolorosa*). Therefore Lipoedema is also called Lipalgie, Adiposalgie, Adipositas dolorosa, Lipomatosis dolorosa of the legs, painful pillar leg or painful Lipoedema syndrome. Whether they all describe the same clinical picture is controversial.

## Causes and Risk Factors

Until today the exact reasons causing the beginning or progress of lipoedema are not known. But since almost only women are affected it seems that hormonal factors crucially influence the illness. Especially the development of lipoedema during puberty, the common worsening after pregnancy and the late occurrence during the menopause indicates this theory. With men lipoedema only occurs in cases of a distinct hormonal dysfunction e.g. after severe damage of the liver (lack of testosterone) or within hormonal treatment (e.g. after prostate cancer). In many cases the illness is more frequent within the family. Therefore a genetic disposition also seems to play an important role.

# Clinical Picture of Lipoedema

## Afflictions

Regarding **body shape** all those affected show a specific increase of subcutaneous fatty tissue on their legs and arms with the torso remaining slim, resulting in a distinct disproportion between upper and lower body. Often they feel as if the lower part of their body belongs to someone else (“Down there that’s not me!”). This partially ostentatious change of body shape often leads to pronounced problems picturing one’s body shape and therefore is a great psychological burden. In many cases the volume of the legs increases so much that walking can cause “chafing” on the inner part of the thighs. In extreme cases pockets of fat developing on the inside of the knees can even cause a **malposition of the legs** as well as **impairment while walking**.

Priority should be given to chronic afflictions such as tenderness or painful pressure as well as recurring spontaneous pain. Tenderness of the tissue can be so much that even the slightest touch feels extremely unpleasant. Therefore lipoedema patients often suffer from a **chronic pain syndrome**. However, there is no connection between severity of increased fatty tissue and intensity of pain, i.e. also in stage 1 of lipoedema massive afflictions can arise. The cause of such afflictions is currently ambiguous.

Afflictions are debilitating because of the swellings. During the day **oedemas (water accumulations)** appear in the subcutaneous tissue of the lower legs but not in the feet, caused by hyper permeability of capillaries for liquid. In the morning oedemas are hardly there or don’t exist at all but are clearly visible in the evenings. Oedemas become more intense by standing or sitting for too long, especially during the hot season of the year.

Another characteristic of lipoedema is recurrent bruises on the legs appearing after light touch or even a nudge. This disposition to bruising is caused by the “brittleness”/impairment of the walls of the smallest blood vessels.

Over the years the medical condition can worsen; the lower legs and thighs are swollen all day long and do not slim over night anymore. This build-up of water causes a **feeling of heaviness and tension**.

The **psychological burden**, which is practically always present, is mainly connected to the recurring pains especially since healing with conservative therapy doesn’t seem possible. Most people affected describe their afflictions with words such as dull, oppressive, heavy, pulling, unbearable and exhausting. After long periods of sitting or standing afflictions can become most intense; those affected characterise

it as “legs about to burst” or “shatter from the inside” or as if their legs are “filled with concrete”.

Many of the affected mistakenly blame themselves for their body shape. Despite all provisions such as dietary change and sport the subcutaneous volume on legs and arms doesn't decrease; the only part getting smaller is the torso, which enhances the disproportion even more. Lack of success leads to recurring frustration resulting in recurring overeating for some of the affected. Therefore an additional surplus weight can occur, worsening the medical condition even further. On top of that, an even greater burden on the psyche is the recurring pains in the legs.

## Diagnosis

It is important to seek an early diagnosis of lipoedema by way of anamnesis, inspection according to the typical characteristics (see chapter: Stages of Lipoedema), visual diagnosis and palpation / squeeze pressure test. Other causes of an oedema must be eliminated which can result in other diagnostic measures.

For a diagnose and follow-up it is recommended to include further parameters such as the weight, body mass index (BMI), “Waist-Hip-Ratio” (WHR), “Waist-Height-Ratio” (WHtR) as well as measuring the dimensions and volume of the extremities and recording a daily activity index. In differential diagnostic difficult cases (adiposity versus lipoedema) such follow-up parameters can be helpful when volume reduction is amiss despite reducing the total weight and stem fat.

Usually technical examination methods are not necessary, however an ultrasound examination as well as a lymphoscintigraphy are helpful to eliminate an associating vessel disease (e.g. varicose, arterial circulatory disorder). It is also possible to prove the characteristic changes of fat tissue and help to differentiate from a lymphoedema.

# Stages of Lipoedema

As the disease usually progresses chronically, various stages according to the severity can be found and are classified according to the visible skin surface and palpation / squeeze pressure test. However there is no connection between the stage of disease and the rate of affliction, i.e. also lipoedema stage 1 can be extremely painful.

Stage	Characteristics	1	2	3
1	Skin surface even, subcutaneous fat tissue thickened and soft without lumps			
2	Skin surface uneven, subcutaneous fat tissue thickened with small lumps			
3	Skin surface very uneven, subcutaneous fat tissue thickened and callous, big fat torus under the skin, in some cases walking is impaired			

Depending on the body part affected different variations of shape can be distinguished.

## Location of Lipoedema

Legs	Arms
Entire leg type	Entire arm type
Thigh type	Upper arm type
Lower leg type	Lower arm type

Often a person can suffer from a mix of the mentioned types. A solitary lipoedema of the arms without the legs affected is extremely rare.

## Progression

The progress in individual cases is not predictable. In most cases however, over time progredience in medical results and afflictions occurs, i.e. an increase in localized accumulated fat tissue lying under the skin and an increase of the oedemas, therefore pain worsens. This increase can happen relatively fast without any obvious reason. There are cases of progression in which a significant worsening happens within a few years, other cases show no changes of medical findings for decades.

A deterioration of a lipoedema is the formation of a secondary lymphoedema. This so called lipo-lymphoedema develops when a lipoedema was not attended properly for many years, i.e. when the legs were not sufficiently treated with Complete



Decongested Therapy (CDP) and no correct compression bandaging/garment was applied. In time an oedema deposited in the soft subcutaneous tissue will cause increase in connective tissue through chronic inflammatory processes. This enlargement of connective tissue leads to progressive induration of originally soft tissue and therefore the lymphatic vessels are being “immured”, restricting the contractility and so the transport of lymphatic fluids is reduced. The inclination of building oedemas increases and additionally leads to swelling in the feet or toes. If the skin over the second toe cannot be lifted off easily any more due to the alteration of the connective tissue it is called a positive “Stemmer sign”.

Another problem that can occur is complications with joints later on. Disproportional fat tissue on the inside of the thighs causes evasive movements of the legs in order to prevent soreness of the skin. For many affected people this leads to knock-knees misalignment and subsequently causes deterioration (arthrosis) in hip-, knee- and ankle joints.

## Differentiation to other ailments

Quite often lipoedema is mistaken for **adiposity** (overweight) of which a large part of the population is suffering. With adiposity however, there is a symmetrical proportional increase in fat tissue over the entire body, i.e. there is no great visible difference between torso and extremities. Women and men are equally affected. The overweight can cause serious secondary diseases (diabetes, hypertonia, high cholesterol value etc.). A crucial part of the therapy is weight reduction by greater energy consumption (sportive activities) and less caloric intake (change of diet).

Also important is the differentiation of lipoedema from **lipohypertrophy**. A disproportionate body shape can also be found here, i.e. a slim torso with a disproportionate big lower body. The increase in fat tissue mostly develops during puberty and is mainly located on hips and thighs (“saddlebags”). Contrary to lipoedema people affected have no oedemas and are not suffering from any pain. Therefore lipohypertrophy is a cosmetic dysfunction while lipoedema is a disease.

Also the **primary lymphoedema** often develops with females during puberty, but can basically occur at any age. It first shows on one lower leg and only later progresses to the thigh. After some time also the other leg is becoming thicker. Since the swelling of a lymphoedema practically always proceeds to the foot the above mentioned “Stemmer sign” is positive. There is no tenderness upon palpation of the tissue or tendency to bruising. The combination in the form of a lipo-lymphoedema is possible.

A further differential diagnose is the **venous oedema**. It develops from a chronic venous disease, i.e. extension of the superficial veins (varicosis) or after thrombosis of the deep veins (post thrombotic syndrome). It can occur with men and women

on one or both sides, mostly accompanied by changes of the skin and subcutaneous tissue such as reddened itchy eczemas, often with brownish skin discoloration and induration of the subcutaneous fat-tissue. At a later stage and upon lack of treatment an “open leg” (*Ulcus cruris*) can appear. Modern i.e. non-invasive and painless examination methods (Doppler ultrasonography, Duplex sonographer) allow the exact recording of the place and extent of venous disorders. But hybrid forms of lipoedema (lip-venous oedema) also exist there.

	Lipoedema	Lipohypertrophy	Adiposity	Lymphoedema
Increase of fat tissue	+++	+++	+++	(+)
Disproportion	+++	+++	(+)	+
Oedema*	+++	∅	(+)	+++
Pressure pain	+++	∅	∅	∅
Tendency to bruising	+++	(+)	∅	∅

Symbol explanation:      + to +++ present      (+) possible      ∅ not existing

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\* Manifestation of the oedemas varies depending on the extent of previous therapy and stage of the illness.

# Treatment of Lipoedema

Pathological increase in fat cannot be reduced by a healthy diet or doing more sports however, additional body weight should and can be reduced by these provisions. An uncontrolled weight gain (yo-yo-effect through strong dieting) should be avoided. Dieting doesn't eliminate the disproportion between a slim upper body and a voluminous lower body because the trunk slims but not the extremities affected by lipoedema. Also, lately available methods to dissolve the fat such as lipolysis injections ("to inject the fat off") or laser lipolysis are – unfortunately – not likely to achieve the desirable extent of reduction. Likewise the use of draining medication is not to be recommended. Such medication may have a short-term effect; in the long run medical results worsen because medication only removes the liquid in the tissue but not the protein parts, which will be deposited increasingly creating callous tissue hindering the lymph-flow.

## Conservative Treatments

The goal of conservative treatments is the elimination of oedemas and pain reduction. At the beginning oedemas mostly occur during the day and are particularly visible in the evenings. Usually such oedemas disappear during the night without further therapy. In this early stage just wearing made to measure compression hosiery during the day can prevent oedemas.

If oedemas don't regress spontaneously any more the Complete Decongested Therapy (CDT) is applied. This physical treatment was developed last mid-century; its essential part, next to compression therapy is Manual Lymphatic Drainage (MLD). Further important elements are movement therapy, skin care as well as training the patient.

The lymphatic drainage mentioned above, performed by specially educated physiotherapists or medical masseurs, is a massage of the superficial tissue (skin and subcutaneous fat tissue) with various pressures. By so-called scoop-, turn- or pump-motions a rhythmic proper motion of the lymph vessels is encouraged, causing an increase in the amount of transported lymph. The treatment starts away from the oedemas at the neck and trunk creating a "sucking"-effect, then the oedematous areas of the legs and arms are treated. Liquids deposited in the tissue are being removed. The compression hosiery applied afterwards supports removing further fluid accumulations and prevents liquids from seeping through again. Movement while wearing compression (bandages, stockings, tights) helps a lot.

At the beginning the treatment for reducing fluid accumulations – depending on the severity of the medical condition – should be done once or twice daily for 45 to 60 minutes over a period of 2 to 4 weeks. Since the first treatment can sometimes

be quite labour-intensive and time-consuming, in hard cases or when outpatient treatment is not sufficient, a period of residence in a clinic specialized in lymphology may be recommended. In the first phase of reducing fluid accumulations during which arms and legs continuously diminish, multi-layered compression bandages with short stretch bandages should always be applied after each MLD.

Upon completion of this phase of oedema reduction, meaning when further progress in volume reduction is not likely any more or only slow progress is possible, flat-knitted compression hosiery – starting from compression class II – is made to measure. During this phase of “optimization and preservation” MLD is mostly required only once or twice a week.

Additionally, only as supplement to MLD, at home the so-called Intermittent Pneumatic Compression Therapy (IPC) a form of pneumatic multi-chamber device can be applied. This device contains of tubular plastic sleeves with 6–12 rhythmically inflatable compartments creating pressure on the tissue towards the heart. To secure treatment success wearing compression garments afterwards is always important. Despite compression slow “seeping through” of tissue fluid cannot be prevented but happens slower than without compression.

***CDT must be applied regularly for life because without it oedemas will build up again.***

## **Compression Hosiery**

Due to the fact that leg dimensions with lipoedema are usually far greater than of normal legs, mainly made to measure flat-knitted compression hosiery with seam is manufactured to ensure optimal pressure distribution. By applying pressure on the skin and especially on the subcutaneous tissue “seeping through” of oedemas shall be prevented in order to stabilize the success of oedema reduction gained with manual lymphatic drainage. Various compression classes (KKL I to IV) as well as various designs of compression hosiery are available. When due to body shape putting on the garments is problematic, often a combination of “Bermudas” or “Capri pants” with stockings is prescribed and must be adapted to individual needs. Good cooperation between doctors, physiotherapists, medical stores and hosiery-manufacturers is essential for therapy success.

Compression hosiery is usually produced as flat-knit-ware or round-knit-ware.

Flat-knit-ware is knitted row by row “to and fro”. The mesh size always remains; increasing or decreasing the amount of stitches at the respective sides achieves the change in shape. Afterwards the sides are sewed together leaving a flat seam lengthwise. This knitting technique allows an anatomically perfect fitting as well as precise compression and progress of pressure. Some materials are characterized by a coarser structure allowing more air permeability and supporting microcirculation.

Thus the therapeutic benefit is much greater compared to round-knitted wear.

The decision which of the various designs and compression classes should be used depends on the severity of the disease as well as the texture of the connective tissue and skin folds.

Care instructions of the manufacturer must be followed accurately in order to preserve compression quality. As a rule, after wearing the compression garments for 6 months consequently they must be replaced.

Flat-knitted compression hosiery should be adjusted and obtained exclusively in orthopaedic specialized shops.

## **Conclusion of conservative therapy methods**

Conservative treatment is a symptomatic treatment reducing fluid accumulations deposited within the tissue and therefore diminishing pains of pressure, tension and touch occurring with oedemas. If the extremities remain oedema-free due to wearing compression hosiery and regularly applied lymphatic drainage, those affected become partially pain-free. Sufficient compression strength as well as a snug fit of the compression hosiery is crucial to therapy success. However, over the years progressive increase in fat can only be slowed down slightly by conservative treatment.

## **Operative treatment methods**

The goal of an operative therapy is removal resp. reduction of pathologically additional fat. Until the beginning of the ninety's liposuction was done with big and sharp tubes under general anaesthetics without previous filling of the subcutaneous tissue with liquid ("dry technique"). This procedure not only left bad cosmetic results in many cases, sometimes also dangerous bleeding and injury of lymphatic vessels occurred.

This method was therefore rightly assessed critically and in the meantime is not used any more. Due to technical and methodical development during the last 10–20 years nowadays, additional fat tissue can be aspirated safely through liposuction with very good effectiveness. Application of local anaesthetics in the form of Tumescent Local Anaesthetic (TLA) and using vibrating micro-tubes – regarding international established guidelines – liposuction with lipoedema is very tissue conserving. Therefore liposuction has become a standard treatment, applied worldwide not only for cosmetic reasons any more but also for medical reasons.

The use of **micro-tubes** with a maximum external diameter of 4 mm has the advantage that small incisions needed for access of the tube are only approx. 4–6 mm long and don't need to be sewed together afterwards but can be taped with butterfly bandage instead. The blunt end of the tube prevents intraoperative damage of the tissue and therefore provides high security with surgery. Through the vibrating

tube only fat lying loosely within the tissue is sucked off, surrounding nerves as well as blood and lymphatic vessels are hardly sucked in and are therefore largely spared.

Where anaesthetic methods are concerned **Tumescent Local Anaesthetic (TLA)** is the method of first choice by now. With this method several litres of a very low concentrated local anaesthetic fluid is infiltrated into the subcutaneous tissue ("wet technique"). With suction a runny fat-liquid-mixture is removed. With every treatment only a certain amount of fat can be sucked off, which is why intervals of a number of weeks/months between the sessions are necessary. Experiences of specialized centres show that in the long run symptoms of lipoedema are significantly improved by liposuction. Not only can harmonic body proportions be achieved by this method, but also oedemas and tenderness of the tissue can be removed or significantly reduced. Treatment can be done out- or inpatient but indication must be assessed individually regarding patient factors.

Since post-operative short-term swelling always occurs, depending on pain sensation physical therapy by way of MLD can be started resp. continued within a few days after an operation. Postoperative a special compression bodice must be worn for 4-8 weeks.

The risk of lymphatic vessel injury as described earlier with subsequent occurrence of a secondary lymphoedema has not yet been experimentally or clinically recognized when liposuction was applied. Long-term check-ups (6-10 years) of various centres resulted in significant improvement of results and afflictions and a reduction of oedema-build-up with all patients treated with liposuction.

As for most persons affected a however slight development of oedema remains after the operative treatment, physiotherapy is continuously an important therapy method just like compression therapy.

Depending on the remaining oedema and the existing leg shape round-knitted or flat-knitted compression hosiery with the necessary compression class is applied – regarding the respective qualities of the knitwear. This is meant to provide further freedom from oedema or pain.

## **Absorption of costs**

If conservative therapy is done health insurance mostly covers the costs (save for a personal share). However there is a limitation to the amount of manual lymphatic drainage (MLD) and of prescribed compression hosiery paid per year.

With an operative therapy in most cases the costs are not paid by the health insurance.

## Specialists

Whether a conservative or an operative treatment is chosen, a qualified professional with appropriate experience must conduct it.

Unfortunately, often general practitioners are not familiar with the symptoms of lipoedema. It is in any case recommended to visit a specialized **Angiologist / Lymphologist / Phlebologist** for backup of the medical outcome, assessment of the degree of severity (stadium) and determination of recommended treatment possibilities – conservative and/or operative therapy. This specialist should be the long-term companion of the patient affected. This includes inducement and prescription of conservative measures, issuing requests for cost absorption for conservative and operative therapies which should be in the best interest of the patient and if needed the introduction of psychological help or support with dietary changes. This is where all ends should meet.

The **physiotherapists** must have special education in manual lymphatic drainage (MLD). In highly developed cases, especially at the beginning of the treatment, a period of residence in a clinic for lymphology may be appropriate. The best possible result in decongestive treatment of lipoedema can be achieved there and a combination with intensive schooling is vital for the rest of the life of a patient. Later on the physical treatment of oedemas can be done by an educated Lymph-Therapist closer to home. In most cases all parts of the CDP can be done outpatient.

Also **liposuction** should implicitly be done in specialised centres and it is crucial that besides necessary instruments (the use of tissue-conserving tumescent local anaesthetics with vibrating micro cannula and aspirator) a surgeon with long-term experience of the medical condition lipoedema handles the case. Due to the necessary pre- and after-treatment a close cooperation between the clinic for lymphology and a lymph-therapist is sensible.

## Self-help for persons affected

To support success of the treatment a healthy diet, sport (no high-performance sport), plenty of exercise, wearing compression hosiery consequently and preventing overweight are important.

Doing **sports** it is recommended to do equally rhythmic activities such as walking, gymnastics, cycling and water sports (e.g. swimming, aqua jogging, aqua cycling). Especially water sports are beneficial because cold water reduces the disposition for oedemas and at the same time the skin is being massaged. There is no orthostatic pressure i.e. loading caused by standing is omitted and additionally many calories are being burned. On the other hand sports causing abrupt stop and go-movements – which are not self-controllable – such as team sports or tennis should be done with caution. In most cases it is sensible to wear compression hosiery while doing sports; by doing movements compression works best for fluid reduction.

Very often **heat** has an increasing effect on oedemas. Therefore excessive sun exposure, solariums, sauna and staying in stuffy hot countries is usually not ideal. Since lipoedema is a lifetime illness, **consequent participation** of the person affected is the most important component of the therapy plan.

Especially wearing compression hosiery daily to prevent oedemas, regular treatment by the physiotherapist to remove the “seeped-through” oedemas and repeated visits at the doctors to control the medical status are essential.



# Swiss Lipoedema Association

The Swiss Lipoedema Association established in 2014 is a non-profit organisation. Its purpose is to be a port of call for persons affected and their relatives, raising doctors and therapist's awareness as well as society awareness in general for this medical condition and to help set up support groups in all of Switzerland. Additionally it is the Association's major concern to push on the acknowledgment of the medical condition Lipoedema and that the Swiss health insurance companies approve of treatment possibilities.

The board members of the association are working voluntary and are all affected by lipoedema.

## Support groups

At the regularly proceeding support group meetings (SGM) members of the Swiss Lipoedema Association can exchange their experiences with comrades in suffering and benefit from it.

Periodically SGM meetings take place in the following areas:  
Sargans, St. Gallen, Zurich, Basel and Bern.

Dates of the meetings can be found on our webpage:  
[www.lipoedem-schweiz.ch](http://www.lipoedem-schweiz.ch).



## ***Die Krankheit Lipödem hat viele Gesichter***

*Picture of a photo-shoot of the Swiss Lipoedema Association*

Link to Lipoedema UK: [www.lipoedema.co.uk](http://www.lipoedema.co.uk).

They offer an International membership of Lipoedema UK for both patients and healthcare professionals, which includes a membership pack including a range of literature for both patients and healthcare professionals.

# Book list on the subject Lipeodema

- **Erkrankungen des Lymphgefäßsystems**

*(Malady of the Lymphatic System)*

Viavital Verlag, 5<sup>th</sup> edition (page 380–412) ISBN 978-3-934371-46-0

Authors: Horst Weissleder, Christian Schuchhardt

- **Dicke Beine trotz Diät - Mein Leben mit Lipödem**

*(Fat legs despite dieting – My life with Lipoedema)*

vg Verlag, ISBN 978-3-86882-567-1

Author: Madlen Kaniuth

- **Das Lymphödem und verwandte Krankheiten Vorbeugen und Behandeln**

*(Lymphoedema and similar maladies Prevention and Treatment)*

Urban und Fischer Verlag, ISBN 3-437-45581-8

Authors: M. Flöte und E. Földi

- **Lipödem Rechtzeitig erkennen und richtig behandeln**

*(An early diagnose of Lipoedema and adequate treatment)*

Südwest-Verlag, ISBN 978-3-517-09383-3

Author: Thomas Weiss

- **Der Patienten Kompass "Der Weg zum selbstbestimmten Entscheid während der medizinischen Behandlung"**

*(The patient's compass "A way of self-determined decision during medical treatment")*

ISBN 978-3-905795-40-0

Author: Barbara Wüst

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- Dr. med. Birgit Wörle, Center for Lipoedema, Clinic Hirslanden, Meggen/Switzerland
- Dr. med. Gerson Strubel, Center for Lipoedema, Clinic Hirslanden, Meggen/Switzerland
- Dr. med. Uwe Lautenschlager, Clinic for Lipoedema, Kreuzlingen/Switzerland



vereinigung lipödem schweiz  
association lipoedème suisse  
associazione lipedema svizzera  
swiss lipoedema association