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NATIONAL LYMPHEDEMA NETWORK

NLN

NATIONAL LYMPHEDEMA NETWORK

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The NLN Mission Statement

The mission of the NLN is to create awareness of lymphedema through education and to promote and support the availability of quality medical treatment for all individuals at risk for or affected by lymphedema.

The NLN is dedicated to:

- promoting research into the causes, prevention and treatment of lymphedema;
- securing adequate insurance coverage for medically necessary, safe and effective treatment;
- expanding the number and geographical distribution of lymphedema treatment facilities and certified therapists.

To achieve these goals, the NLN disseminates information about lymphedema to health care professionals so they can appropriately counsel their patients on its avoidance, and prescribe safe, effective treatment for those affected by this condition. The NLN also provides this information to the general public.

Understanding Lipedema

Guenter Klose, CI, CLT-LANA, and Roman H.K. Strößenreuther, MD

The term "lipedema" was first used in 1974 by ALLEN and HINES. Their publication is regarded as "the classical description" of the syndrome^{5, p. 184}.

"We wish to describe a clinical syndrome, lipedema of the legs, which is frequently very distressing. In our experience it affects solely women. The chief complaint is of swelling of the legs and feet... On questioning, the physician may elicit that enlargement of the limbs has always been generalized and symmetrical. The swelling below the knees is accentuated when patients are on their feet much and in warm weather. Aching distress in the legs is common... Occasionally, a patient feels, that her large legs have 'ruined her life.' Many are 'ashamed' of their legs."

This describes the patient's problems very well, but it is difficult to define lipedema precisely because the definition depends mainly on subjective findings. There are no medical or laboratory tests to distinguish local lipohypertrophy (local fat tissue increase) of the legs or hips from lipedema or general obesity. Consequently, lipedema is not generally accepted as a real disease. We will attempt to describe the current knowledge on the pathophysiology and treatment of lipedema.

Lipedema is a metabolic disorder of the adipose (fat) tissue with unknown etiology, affecting almost exclusively females. The following clinical and pathophysiological findings are of importance for differential diagnosis.

The term "lipedema" was chosen by ALLEN and HINES^{5,128} to describe a symmetrical swelling of both legs, extending from the hips to the ankles and excluding the feet, caused by an abnormal amount of subcutaneous adipose tissue. Typically, bulging masses can be found in the proximal thigh region and at the medial aspect of the knees. Occasionally, large, overhanging and hypersensitive fatlobes develop in these areas^{5,22,32,33,36,38}. In others, contours of the legs are more funnel-shaped, with a decrease of the adipose tissue noted below the knees. Some individuals present with similar changes in the arms especially when patient is also obese^{33,38,95}.

Most patients report slow onset of symptoms, often in connection with beginning of puberty^{33,35,36,49,86}; in other cases, there is no specific time of onset^{5,36,42,48,128}. Some patients report that other females in the family also suffer from lipedema^{42,59,132}. ALLEN and HINES¹²⁸ found a positive family history in 20%(n=119), but epidemiologic studies concerning

lipedema do not yet exist. There is no evidence of a specific genetic disorder or incidence related to race¹²⁸.

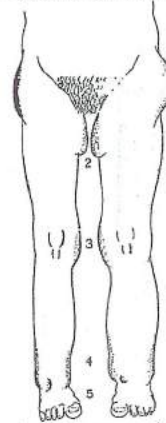


FIGURE 1: Typical distribution pattern of the increased fat masses: 1=hip cushion; 2=proximal thigh bulge; 3=medial knee bulge; 4=fatty cuff at the malleoli; 5=local pre- or retromalleolar lipoma²².

Numerous impairments result from the abnormal pathophysiology of the tissues. The epidermis and subcutaneous tissues of the lipedematous

legs show a decreased elasticity^{5,42,66,67,128}. Aging causes further loss of skin elasticity^{18,80} and progression of the condition^{5,38,41,42,66,67,128}. Problems with normal ambulation (walking) lead to secondary orthopaedic deformities of the knees and feet^{16,17,22,33,36,38,42}. The tissue resistance to the contracting calf muscles (calf muscle pump) is too low and results in passive hyperaemia and an increase infiltration of water through blood capillaries, resulting in increased lymphatic water load. Swelling occurs when this fluid load exceeds the transport capacity of the lymphatic system^{42,66,67,80}. Blood capillaries are fragile and even insignificant trauma (e.g., hitting the leg on a table corner) can cause the development of small haematomas and a further increase in lymphatic load^{5,33,42,59,128}. Blood

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Understanding...

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coagulation tests for this condition are typically normal. It is not surprising that many patients develop an emotional disorder considering the physical appearance of the legs ALLEN and HINES pointed out:

"Patients with lipedema ordinarily are very sensitive about the appearance of their legs; they wear long skirts, avoid appearance in swimming suits and stand behind chairs at parties ... They are likely to be mirror peepers, searching repeatedly in mirrors for evidence that the appearance of their legs is not actually as bad as it seems to be"^{128: p.1245}. Evidence of neurosis is likely to be found. Occasionally, a patient feels that her large legs have 'ruined her life.' Many are 'ashamed' of their legs"^{10: p.55}.

One patient described her situation:

"When you become older, you also become a little more overweight and your legs 'go through the roof.' You develop constant rubbing between your thighs; in summer it is itching and becomes sore. With age you also become more lazy—and, because of this constant itching and pain, you don't see any possibility for doing exercises. As the obesity worsens, lower back pain develops, the joints begin to hurt and your friends make silly jokes about your shape—and finally you rest at home, your only consolation is the chocolate in your nightstand and you will be unable to get out of this vicious circle!"

After some years, in cases of coexisting general obesity, lipedema can transform into lipo-lymphedema (STEMMER's sign is now positive) in which fatty tissues begin to hold fluid¹⁴³. Furthermore, there is a correlation between obesity and disturbances of vascular edema protective reflexes^{9,24,25,51,52,53,54,60,65,79,85,100,101}, which leads to additional lymphatic water load. Edema is always the result of lymphatic insufficiency and, indeed, the lymphatic system shows typical pathological changes. The pre-lymphatic channels are widened; lymphatic capillaries have aneurysm-like changes⁶² and we find an irregular corkscrew-like course of the lymphatic vessels^{42,107,117}. The increased adipose tissue and the enlarged adipocytes most likely deform these thin lymphatic structures^{42,123}.

When lipo-lymphedema is present, pitting (indentable) edema in the lower legs can be noted when the person is upright or walking. This edema causes an uncomfortable feeling of tension. A reversal of the edema is possible after elevation

of the legs for a longer period or overnight^{5,41,42,49,127}.

Scintigraphy of the lymphatic system^{2,93,116,117,118,124} shows contradictory results. Sometimes, a reduced outflow in comparison to normal persons is described^{17,117,123} and other times, normal results were found^{21,124}. The decreased transport capacity of the lymphatics due to aging develops faster than in healthy legs⁴².

Unfortunately, there are no universally accepted guidelines for diagnosis of lipedema and, in some cases, the differentiation between lipedema and lipo-lymphedema is difficult^{47,119}. The typical progression of lipedema is as follows:

- In the **first stage** of the disease, the skin of the legs appears soft, smooth and regular. But palpation reveals changed structures of the adipose tissue that have a resemblance to "small Styrofoam balls"¹¹².
- In the **second and third stage**, the tissue structure becomes more and more nodular and tough, developing large deforming fatty lobes^{35,123}, especially at the inner side of the thighs, the knees and above the ankles^{22,42}.

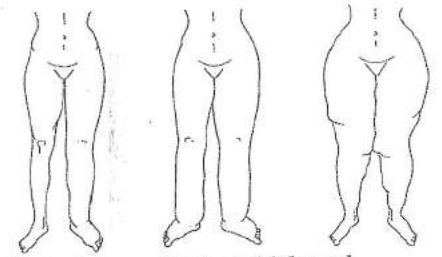
DIFFERENTIAL DIAGNOSIS

The diagnosis of lipedema can be difficult in the early stage or if a combination form exists. Differential diagnosis of LE and lipedema is, in most cases, possible by taking the medical history and evaluation of the STEMMER's sign. Distinction between primary bilateral lower extremity LE and lipedema can be difficult, although bilateral LE usually presents asymmetrically in contrast to symmetrical presentation of lipedema^{4,22,42,89,94,113}.

TREATMENT OF LIPEDEMA

While some of the pathophysiological tissue changes contributing to lipedema

FIGURE 2:



Typical shape of uni- and bilateral lymphedema and lipedema (l to r).

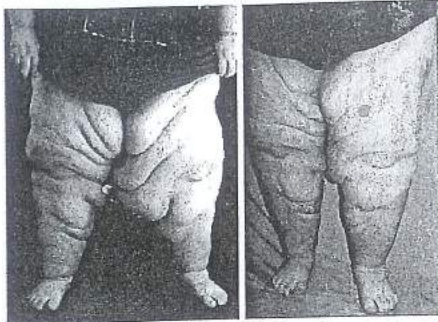
are identified, the real cause of the disease remains unknown. Therefore, therapy is predominantly symptom oriented. The goal must be to improve the disturbed lymph transport, the pathophysiological changes in microcirculation in the enlarged adipose tissue and a reduction of pain and the fat masses.

The most common therapeutic intervention for lipedema is Complete Decongestive Therapy (CDT)^{34,37,42,125,127}. The main constituents of this therapy concept are Manual Lymph Drainage (MLD)^{144,433} and compression therapy^{5,15,42,99,108,128}. Diet, skin care and remedial exercises are also very important.

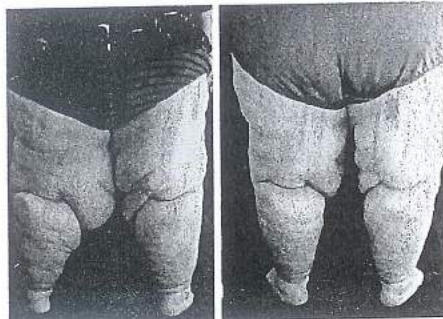
At the *Lymphologica* 1999 in Marburg/Germany, BRENKE reported, a volume reduction of 3.2 liters after a 3-week intensive therapy (mean initial volume of 23.3 liters; the average volume reduction at the thighs was 2.85 liters). In our Department of Lymphology (Freiburg/Germany), the mean volume reduction after 2 weeks of CDT is 14 % on average.

After initial decongestion through MLD and compression bandages, the patients are fitted with custom-made compression stockings. Permanent compression therapy causes significant reduction of adipose tissue^{15,35}, has a positive influence on the disturbed veno-arteriolar response and improves relative insufficiency of the

DIFFERENTIATION	LIPEDEMA	BILATERAL PRIMARY LYMPHEDEMA
Sex	almost exclusively women	more women than men
Beginning	often with the menarch	often with the menarche
Development	simultaneous begins at the whole legs	usually distal beginning
Extent	from the iliac crest to the ankle; no involvement of the dorsum of the feet	whole leg, involvement of the dorsum the feet
Stemmer's sign	negative	positive
Distribution	symmetric	asymmetric
Pain/hypersensitivity	yes	no
Skin temperature	decreased	normal
Skin color	normal, sometimes pale or cyanotic	normal
Haematoma	yes, even after minor injury	no
Tissue consistence	for a long time very soft tissue; later development of fibrosclerosis	progressive lymphostatic fibrosclerosis
Edema	pitting edema of the lower legs only after prolonged orthostasis	pitting in stage I, later fibrosclerosis
Dorsum of the feet	no edema	edema in most cases
Hyperkeratosis	no	yes
Cellulitis	no	often
Influence of positioning on edema	only decreases the orthostatic edema	significant decrease only in state I



Left 2 photos: Patient with lipo-lymphedema; before treatment and after 4 months of in-patient Phase-1 CDT given within one year. Weight reduction was 60 kg and leg volume reduction of 21 liters. Right 2 photos: Same patient, posterior view.



and improves relative insufficiency of the venous pump of the lower legs.

Exercise and sport activities are recommended, but the effect on adipolysis or the loss of leg and hip fat is often disappointing. Nevertheless, some younger patients report an improvement when working out 4-5 times a week, a minimum of 45 minutes and with an exertion rate of 75% (related to the maximum heart frequency). This recommendation may be unrealistic for some women. Some patients feel a positive effect after KNEIPP (hydrotherapy) applications; currently there is no research available concerning this therapy method.

Weight reduction is absolutely essential if patients are overweight because lipo-

lymphedema may develop particularly in patients who are also obese⁶⁸. There are, however, no specific dietary recommendations for lipedema.

Additional therapy with external pneumatic compression is sometimes recommended¹²⁶. Some patients report positive results with pneumatic compression, but controlled studies do not exist. ALLEN and HINES⁵ and others consider the use of diuretics a mistake.

In some select cases, liposuction has been recommended for the treatment of lipedema. Surgeons have shown good results, but problems also exist. After liposuction, some patients develop chronic lymphedema^{40,123,127}, lymphatic cysts or large haematoma⁶³ and have

problems with wound healing. Moreover, the cosmetic results are not always satisfactory⁶⁹. In recent years, the technique of liposuction has improved, and complications are fewer. Experience with a small number of patients indicates that the combination of surgical techniques with CDT may help to improve the results of liposuction. (Schmeller et al: Dtsch Arztebl 2005; 102:A 1061-1067 [Heft 15]). No definitive studies are available to confirm this finding.


CONCLUSION

Lipedema must be differentiated from local lipohypertrophy, primary LE of both legs and general obesity. Until the real cause of lipedema is known, treatment is symptomatic. With adequate treatment and optimal patient adherence, good results can be achieved, progression of lipedema can be halted and additional health problems prevented.

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References available through the NLN office or at www.lymphnet.org.



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Question Corner

Kathryn McKillip Thrift, BS, CLT-LANA

Q: What is lipedema?

A: Many believe lipedema is an abnormal accumulation and storage of fat in the tissues. Why it occurs is not understood. Lipedema occurs predominantly in women, often occurring or increasing in severity at puberty, pregnancy and peri-menopause. Usually, it runs in families and occurs in the legs, but occasionally, it appears in the arms, as well.

There are some classical signs of this condition which include a "wall" or "bracelet effect" at the ankle. Usually, the foot is not involved unless LE develops, which often happens after a number of years if the lipedema is left untreated. The legs, which typically look like mirror images of each other, are often tender and bruise easily. They may look like columns (i.e., there does not seem to be much definition in their shape). The classical picture of a woman with lipedema is one who looks like a size 8 above the waist and size 16 below the waist—top half and bottom half of body don't seem to match.

Q: Recently, I started seeing a new massage therapist who has been trained in Manual Lymph Drainage (MLD). She told me I possibly had the condition called lipedema. As she was describing the signs (both my legs are heavy and equally so; there's a "bracelet" effect at my ankles and my feet are not swollen; my legs are extremely tender and I bruise easily), I nearly cried as she was describing me exactly. How can I find a physician who knows about this condition?

A: Although first described in the '40s at the Mayo Clinic by Allen and Hines, little is known about lipedema in this country. There is a limited number of doctors in the U.S. and Canada who truly know about this condition, unlike Europe, where it is a commonly known and diagnosed condition. Physicians and therapists who are LANA certified are familiar with lipedema. Check the resource guide at www.lymphnet.org and www.clt-lana.org for a physician/therapist in your area. There are a few articles listed under lipedema on www.google.com that you could print out to take to your physician.

Q: Is there anything that can be done for lipedema?

A: Since little is known about the cause of lipedema, the best answer is "it depends." Now, let me explain. If you mean: can lipedema receive therapy that will help reduce the pain and possibly the size of the legs? Then yes.

Manual Lymphatic Drainage (MLD) has been found to be effective in managing this condition.

If you mean: is there a cure? Then sadly, the answer is no. Because the cause is not known, a cure is not possible. However, with Complete Decongestive Therapy (CDT), the symptoms can be well managed. Following CDT treatment, compression stockings can help control the condition by preventing the dependent edema that occurs in the legs during the day. However, the number of fat cells will not be reduced.

Diet has not been found to be particularly effective in managing lipedema. Many have found it extremely difficult to lose weight and have battled their weight for years. Recent research suggests that diets that reduce inflammation might be beneficial. The thought behind this is that fat produces inflammation in the body; therefore, a way of eating that helps to reduce inflammation might help with lipedema. Stay tuned for future developments in this new light on the condition.

Q: Since lipedema has fat deposits, would liposuction benefit someone who has lipedema?

A: This is a controversial subject. It would appeal to one's sense of logic that if the trouble is an extra amount of fat deposited under the skin, then liposuction should help. Here's part of the reason this may be a faulty belief: the amount of fat that would have to be removed to make a sizeable difference in the look of the legs would be too great for the body and death could occur. According to the website, www.liposuction.com, Standards of Safety dictate "...the maximum amount of fat that can be removed safely is probably about 6 to 8 pounds.

"Whenever large volume liposuction has been used to attempt to treat obesity by surgery, there has been a significant increase in the incidence of serious surgical complications. [In other words, it] can be fatal. [Since] it is not safe to remove huge amounts of fat by liposuction...[it] will not be of any significant benefit for an obese patient who believes liposuction will aid in the effort to lose weight. Liposuction is not a good treatment of obesity. Liposuction is not effective, even as a last resort, for people who are unable to lose weight by dieting and exercise."

Some plastic surgeons do think the newer tumescent wand could cause less damage to the lymphatic system and be less harmful. Perhaps, some sculpting can be done after there has been weight reduction, but it should never be used instead of weight reduction.

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LSAP Review...

Continued from page 10

children facing a lifetime of treatments from lymphatic disorders.

The entire Conference was motivating and brings forth new opportunities. As advocates, we are the conduit between those who suffer from and treat LE and the general public who may have never heard the term. It will require lots of effort, but the journey has begun. I know that it is already happening for me, through the Breast Cancer Awareness programs.

As the Conference came to a close, my brain felt like a giant swollen lymph node in need of gentle and complete decongestive therapy. However, through the advocacy program, there is an avenue through which the information can flow and spread out to the world.

My special thanks to my fellow LSAP advocates, Pat O'Connor, Joan White, Bob Weiss, Debbie Miles, Jennifer Fortener and Anna Kennedy for their diligent work and for making me feel welcomed and excited, and most importantly, to Saskia, for gently persuading me to attend this Conference. Also, to Carmelita Rifkin, PT, for insisting I buy the red lymph-kicking cowgirl boots to begin my work.

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