

Lipedema is generally thought to be an abnormal deposition of subcutaneous fat with an associated oedema

Lipoedema

Lipedema

Lipoedema – and what you ought to know about it.

Here you will find out everything that you ought to know about lipoedema:

What is lipoedema?

What can I do about it?

How does it make its presence felt?

What are the most frequent symptoms?

What therapy methods are available?

What should the affected patient be aware of?

Frequent symptoms

Lipoedema leads secondarily to a chronic lymph blockage. The fat lobules and fat cells are anchored in the connective tissue where they are surrounded by very small lymphatic and blood vessels. An increase in the fat cells gradually results in the finest lymphatic vessels being pressed shut. In addition, oestrogens (female sex hormones) cause an increase in the storage of fluid in the connective tissue and a loosening of this tissue.

One side-effect of lipoedema is therefore a chronic lymph blockage in the dependent parts of the body and the storage of fluid in a very loose connective tissue. This explains the pains that regularly occur.

Lipedema seems to affect all races

Feeling of heaviness in the legs

This is caused by the weight of the increased adipose tissue and the amount of accumulated tissue fluid.

Swollen legs (orthostatic syndrome)

It is mostly during long periods of standing and/or sitting that the accumulation of fluids in the legs increases. The result is a swelling, frequently accompanied by a tendency to swell in the (otherwise not affected) feet. People affected by this often say that they have trouble putting their shoes on in the afternoon.

Orange skin phenomenon and cellulitis

Caused by the special structure of the connective tissue and the loosening of this tissue.

Increase in the occurrence of bruises (haematomas) in the affected parts of the body (even at the slightest inducement)

The reasons for this are:- pressure on the blood-vessels by the fat cells; a lack of anchoring of the small capillaries in the connective tissue, which results in them tearing when affected by the pull of gravity.

Considerable pain in the legs; painful sensitivity to touch

The continued development (chronification) of the lymph blockage leads to a hardening of the tissue (induration), which can be extremely sensitive to touch and very painful.

Early occurrence of degenerative changes in the joints and arthroses

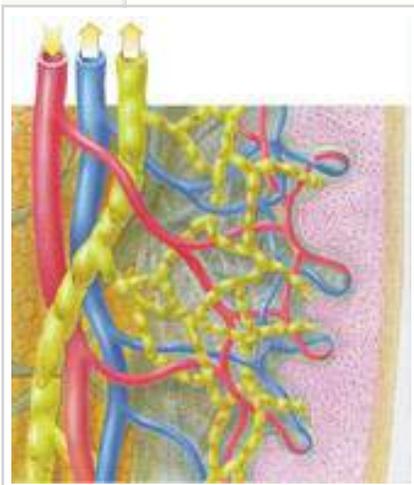
Especially in the knee (because of wrongly placed stress and excess weight).

Function of arteries, veins, and lymphatic vessels

red = arteries

blue = veins

yellow = lymphatic vessels



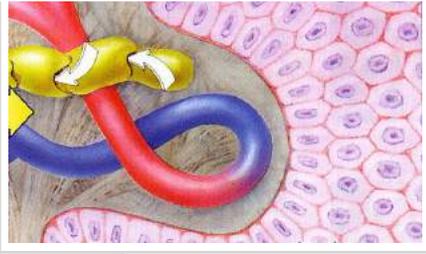
Blood is pumped along the arteries right down to the big toe. 90% of the blood flows back to the heart through the veins.

The remaining 10% is carried back along the second return flow system, the lymphatic vessels, to the main circulatory system.

Lymphatic vessels Lymph fluid is absorbed from the lymphatic vessels by small pores and pumped upwards.

Constriction of the lymphatic vessels





Constriction of the lymphatic vessels by an increased fat deposit.
The return flow of the lymphatic vessels is thus blocked.

Classification of the lipoedema (5 types)

Type I

Type Ia: without pain

Type Ib: with pain

Increase of the adipose tissue in the region of the pelvis and the backside (jodhpurs phenomenon)

Type II

Type IIa: without pain

Type IIb: with pain

The lipoedema goes as far down as the knees

Type III

Type IIIa: without pain

Type IIIb: with pain

Marked clinical picture of a lipoedema from the hips down to the ankle (Suaven trousers phenomenon)

Type IV

Type IVa: without pain

Type IVb: with pain

Special particularity: the arms are affected.

Type V

Type Va: without pain

Type Vb: with pain

Special particularity: restricted to the lower leg

Combinations of the types are possible.

Stages of lymphatic oedema

Lymphatic oedema, which appears secondarily in lipoedema, i.e. as the consequence of the increase of

adipose tissue, is frequently divided up into 4 degrees of severity in medical literature (see below):

Stage I

Can be depressed, and is spontaneously reversible. Is apparent after physical strain or at the end of the day, and has gone again after a night's rest.

Stage II

Can be depressed, and is reversible after treatment. Complications such as eczema and erysipelas frequent. Without therapy is less severe in the morning, but is still detectable.

Stage III

Connective tissue hardened (fibrosclerosis), cannot be depressed. Can only be improved, but even after therapy damage to the connective tissue still present.

Stage IV

Irreversible oedema, elephantiasis; complications up to malignant degeneration.

Presence of superficial varicose veins

Of the blood that is pumped by the heart along the arteries to the legs right down to the big toe, 90 % is transported back to the heart in the veins. However, nothing can flow of its own accord against the pull of gravity, i.e. upwards. The blood must be pumped upwards actively. This is done with every movement of the legs, with every stride. That is why there are flaps in the big veins at short intervals. The venous flaps work in the same way as a valve and only allow the blood to flow upwards. These flaps frequently get damaged or even destroyed in the event of a thrombosis. In a genetic weakness of the connective tissue the veins frequently stretch in the course of years or decades to such an extent that the venous flaps can no longer close and the blood flows back into the leg again. This is helped by factors such as professions involving sitting or standing, pregnancy, hormone treatment, extreme overweight, and heavy physical labour (especially in a hot environment). The veins which expand because of this are called "varicose veins".

Damage to the deep-lying venous system

It can however also affect the deep-lying venous system, which is as a whole much more important for the circulation and whose transport capacity is four times as great as that of the superficial system. Because of the pressure of the column of blood in the varicose veins or in the deep-lying veins, fluid and/or solid substances are passed into the tissue ("interstitial space"). This fluid is usually

transported back to the heart along the lymphatic vessels. The remaining 10 % is filtered off in the system of the capillaries as an albumin-enriched clear liquid which is called lymph.

Because of the increase in the weight of the lymphatic fluid an even greater strain is placed on the transport capacity of the lymphatic vessels, which are already being pressed shut, and they swell. For this reason a phlebological examination of the venous system must also be performed as a matter of course in patients with lipoedema, since varicose veins can be both avoided and also well treated.

Great physical strain

An increase in the weight of the lymphatic fluid can also occur as the result of too much physical activity. Here, of course, the limits vary according to the individual. With the increase in the demand for oxygen and energy by the muscular system of the legs during generally unusual physical exertion, the heart has to pump more blood into the leg per time unit, and the cardiac output rises. 10% of this accumulates in principle as lymphatic fluid; because of this the strain on the lymphatic system is increased. Some patients report an increase of the pains after stimulating drinks such as coffee, coke, tea, wine, or sparkling wine. Caffeine and alcohol stimulate the microcirculation in the capillaries, thus causing an increase in the demands on the lymphatic system.

First complication

Of all the possible complications, the ones to be named first and foremost are the diseases caused by wear and tear of the joints (preferably of the lumbar vertebrae and of the pelvic, knee, and foot joints).

Second complication

A second complication is the development of lymphatic oedemas. Especially in stage III of the lipoedema there is a disorder of the lymphatic flow which is due to the increasing stenosis of the lymphatic vessels by the sudden growth of the adipose tissue. At a more advanced stage of the disease large-sized lymphatic oedemas can occur in addition to lipoedema. In contrast to pure lymphatic oedemas, which usually bear different characteristics on both sides, the development of a lymphatic oedema in the course of a lipoedema disease is always symmetrical.

Third complication

Increase in weight! In particular – as stated at the beginning – psychically depressive factors can frequently cause an increase in weight in lipoedema. Because of this the risk of additional complications, such as diseases caused by wear and tear of the joints or the development of a lymphatic oedema, is dramatically increased.

Treatment possibilities are restricted

1. Diets and fasting

Lipoedema is not caused by nutrition, and therefore can not be influenced by diets or fasting! Patients frequently suffer from a severe loss of their self-esteem. Only too often they are told that their disease is the result of the wrong nutrition. They hear this not only from their family and their private/professional sphere, but unfortunately also from inexperienced paediatricians and general practitioners. Because of this massive external influence, many people genuinely believe in the end that the symptoms are the result of the wrong nutrition and start their first cutting-down diets.

However, the weight reduction achieved by this has no influence at all on the leg circumference. Besides which, a diet makes the organism change over to low-flame, so that the subsequent “normal” eating habits, when resumed, lead to a sudden increase in weight (usually in the legs first of all!).

Nutritional disorders are however frequently a side-effect of lipoedema. At the latest when the legs become sensitive to touch, and pain and haematomas occur on every touch, the sex-life is impaired to a very great extent. One result of this is that the affected people often look for a substitute satisfaction, frequently in an excessive food intake. In many instances this results in a nutritional disorder that needs to be treated. Here a stay in a hospital specialising in lymphatic disorders gives the patients the opportunity to get back to normal eating habits again.

2. Medicinal treatment

Lipoedema cannot be influenced or healed with medicines (neither by pills nor by creams)!

3. Sports

The ideal sport to go in for with lipoedema is swimming. Here the muscular activity takes place in a horizontal position, so that there is no danger of the threat of an oedema which occurs when the body is upright (orthostatical syndrome). Cycling is also good for you. Gymnastics, going for walks, and light jogging can also be recommended.

4. Cosmetic corrections

Liposuction (suction of the fat) is a method of treatment that is frequently applied. It must be admitted that in the past no improvement was observed in a few instances. If the lymphatic vessels are damaged during the procedure the result can even be a deterioration. Before you decide to have liposuction you should get someone to tell you about all the side-effects, the expense it involves, and the long-term results of this method.

PLEASE Consult several doctors!

5. Lymph drainage and compression treatment

The only recognised and highly effective method of treatment is the combination of manual lymph drainage and compression treatment. Hereby the lymphatic vessels are opened by means of a special massage technique. In the course of one session of e.g. 45 minutes approximately 500 ml of lymph and water are moved out of each leg in the all-round treatment. In order to make the effect last longer, both lymph and blood have to be pressed into the lower-lying larger veins or lymph collectors.

In addition the provision with medical compression stockings or tights is absolutely essential.

In lipoedema the legs are often beyond every standard size, so that made-to-measure stockings in high compression classes are necessary. Intermittent compression treatment with apparatus containing several chambers seems to have a favourable effect on lipoedema and is necessary as an additional therapy when the amount of manual lymph drainage (MLD) cannot be increased.

Treatment as an out-patient or an in-patient?

People with Stage I lipoedema are normally treated as out-patients. From Stage II onwards treatment in hospital must be taken into consideration at least as an initial measure. There are several reasons for this:

1. The disease needs continuous treatment. If it is interrupted or discontinued the findings and the pains will deteriorate more or less quickly. The suffering is constitutional; there is therefore not one cause which can be resisted therapeutically.
2. The patients, who are very often young, have to be convinced of the necessity of wearing compression tights consistently. It is natural that this will be more likely to succeed when an effect is visible. Treatment as an out-patient certainly produces a clear reduction in the pains in many instances, but not, however, an appreciable reduction in the circumference of the legs.
3. In most instances the patients have a very disturbed feeling of self-esteem (the younger they are, the more frequently). It is often a help for them to be in a group with fellow-sufferers who are faced with the same problems and with whom they can exchange stories of their experiences. After having been to a hospital specialising in lymphatic disorders many women seem to be internally transformed and have a positive attitude to their lives again.
4. From Stage II onwards an effective de-blockage, which accompanies a measurable reduction of the circumference and volume (approx. 1 – 1.5 litres per leg or 5 – 12 cm less on the upper leg), can no longer be achieved in by a lymphatic therapist working outside a hospital because of the amount of time needed for this.

In-patient treatment in a hospital specialising in lymphatic disorders.

Optimal treatment, such as can only be performed in a hospital specialising in lymphatic disorders, looks like this:

1. Manual lymph drainage in the morning and in the evening as a total treatment for the duration of at least 45 mins., with simultaneous breathing exercises and anti-blockage exercise-movements.
2. Subsequent bandaging of the legs with special foam rubber, textile-elastic short stretch bandages.
3. If necessary intermittent compression for 30 – 60 minutes (if necessary twice a day).

There are in addition supportive measures such as:

- advice on nutrition
- reduction and wholesome diets
- pain therapy
- bicycle ergometer training
- long walks
- psychological counselling

Female patients are occupied with this therapy all day long. It is only through these intensive measures that appreciable reductions in the circumference can be achieved. During the first two weeks the success of the treatment is relatively small. In most cases the greatest progress is to be expected after approximately 4 weeks. In severe forms with the second stage of lymphatic oedema it may be necessary to carry on the treatment for longer.

During the day

- Do special anti-blockage gymnastic exercises in compression stockings – if prescribed by the doctor.

During the night

- If prescribed – put a bandage on the affected extremity after careful skin-care!
- Put the affected arms or legs up! (If necessary raise the end of the bed).

Holidays

- Avoid tropical regions (heat, insects)! Take antibiotics with you in case of emergency. Your doctor will tell you the dosage).
- On long journeys have breaks so that you can do gymnastic exercises (in the aeroplane, if possible,

get up and walk about
again and again: do rocking movements with your feet).

Physiotherapy/remedial gymnastics

- No kneading massage!
- No fango packs in the oedematous area!
- No deep-heat-producing electrotherapy!
- No overstretching remedial gymnastics!

Doctor

- Do not measure your blood-pressure on the affected arm.
- Do not allow any phlebography or direct lymphography to be performed on the swollen limb!
- Do not accept manual lymph drainage as an isolated therapy! (Compression treatment is absolutely essential!) In manual lymph drainage the affected quarter of the body or the entire body must always be lymph-drained.

Go to a doctor immediately if ...

- pains occur and/or the muscle-power diminishes.
- the swelling deteriorates in spite of adequate treatment.
- inflammation of the legs occurs with pain, redness, marks, or shivering fits (erysipelas = erysipelas infection).

Nutrition

- Keep to your optimal weight or, if you are overweight, try and get back to it by dieting and exercise!
- Make sure you have a balanced diet! Eat a lot of vitamins! Avoid sugar, sweets, and things made with white flour
(cake, biscuits, etc.)
- Restrict the amount of salt you eat. Drink when you are thirsty; in other words, you may drink as much as you want
(at least two litres a day).

Garden

Avoid injuries (thorns, prickles, tools).

Pets

Avoid at all events being bitten, or scratched by a cat.

Subsequent out-patient treatment

After having provided the patient with compression stockings a consistent permanent continuation of this treatment must take place at home:

Manual lymph drainage once to twice a week, the permanent wearing of compression tights, and, if these measures are not sufficient, the additional prescription of an apparatus for mechanical intermittent compression by the general practitioner in charge or a phlebologist. These measures serve to ensure the success of the treatment in the hospital specialising in lymphatic disorders.



In many cases this may be sufficient. Frequently, however, the situation occurs where, in spite of good coordination with the patient and the raising of the weekly lymph drainage, extra hours in the “lymphomat”, and if necessary also a rise in the compression by means of stronger and/or additional compression stockings, an improvement is not achieved, but instead a continuous deterioration occurs. This can make itself manifest in the form of an insidious increase in the circumference and/or an increase in the blockage problems/pains.

If this happens in spite of an open-minded and active cooperation in the therapy on the part of the patient, i.e. if there can be no question of compliance problems as the explanation for this, another in-patient stay in a hospital specialising in lymphatic disorders cannot be avoided. And over the course of the years additional in-patient treatment will have to be considered when the possibilities of out-patient treatment in that place have been exhausted.

What the female patient should be aware of: at home and at work

Avoid injuries, strain, extreme temperatures (heat and cold)!

Clothing

Skirts, trousers, and belts must not exert pressure – free breathing is important!

Cosmetics and body-care

- When caring for your nails do not cut into the nail wall!
- Do not use cosmetics that irritate your skin!
- Do not use alkaline soap; use a soap with an acid pH value – the acid protection layer of your skin must not be damaged. Your skin must not be dry or cracked.
- Take care in the sauna! It can be harmful, but may not be.
- Take care when sun-bathing! You must at all events protect your skin from sunburn!

- Avoid kneading massage of your leg and the lower backside of the same side!

Sports

In general, going in for sports is advantageous. The de-blocking effect of sporting activities is increased even more if you wear compression stockings.

- Get your doctor to fit you out with compression stockings from the range of the well-known Bavarian manufacturer Juzo. With the SkinProtect® procedure specially developed by Juzo the fine mesh becomes extraordinarily pervious to air and moisture and is therefore pleasant to wear.

- No sudden movements of the swollen extremity (take care in sports such as tennis, squash, football etc.)

- Do not get frostbite if you go in for winter sports!

- Do not risk getting injured! (Choose cross-country skiing in preference to alpine; gentle swimming is one of the therapeutic methods).

What is Lipodema

Lipodema is a **medical condition** that is often confused with lymphedema. The individual with this condition may appear to be simply obese and/or to have extremely swollen legs and swollen abdomen. The condition is an uneven distribution of fat cells in the sub-cutaneous regions generally in the legs or abdomen. **One major frustration of people with lipodema is that they are accused of being simply "fat," which is absolutely not the case.**

Etiology/ Cause: Unknown

Complications:

Perhaps one of the most critical complication is the acquisition of secondary lymphedema. The increased weight can crush the lymphatics causing blockages and hindrances to lymphatic flow. Another complication is deterioration of the joints and vertebrae from the excessive weight. Other complications may include varicose veins and/or the deep venous system. Many lipodema patients also experience a tremendous amount of pain due to the condition and the affects on the body's systems. Other complications may include "pins and needles" discomfort, decreased vascular flow in the affected limbs and a decreased skin temperature in the affected limbs.

Treatments:

There is no known "cure" for lipodema. Because it is not a medical condition caused by over-eating

and improper nutrition habits, diets will not have much of an effect. Neither can the condition be treated with medicines or diuretics.

Treatments that have helped include massage therapy in conjunction with compression bandages, benzopyrones, which includes the use of coumarin. Liposuction has also been used, but the long term success is still open to debate.



Lipodema or Lymphedema??

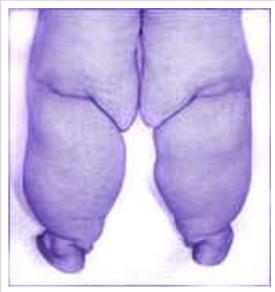
The signs of lipodema are distinctly different from lymphedema. First, swelling does not extend to the feet, but extends from the abdomen to the ankle. Second, the limb texture is rubbery not hard. Third, pitting edema is not present. Fourth, Stemmer's sign is negative and finally infections that plague lymphedema patients are generally not a problem with lipodema. The reason for this is that lipodema is not caused by a malformed or damaged lymphatic system.



NOTE: Lipodema and lipo-lymphedema can also occur in the arms and chest. Normally, abdominal and thigh deposits will also be evident when this occurs. However, this is not always the case.



Abbildung 1a: Lipödem Stadium I. Abbildung 1b: Lipödem Stadium II. Abbildung 1c: Lipödem Stadium III.



30 may 2005 LYMPHATIC DISTURBANCES IN LIPOEDEMA

Prof P.S. Mortimer, London, UK

Van Geest A.J., Esten S.C.A.M., Cambier J-P.R.A., et al. *Phlebologie*

. 2003;32:138-142.

ABSTRACT

This study by Geest and colleagues investigates possible **lymphatic abnormalities in lipedema**. Standard web space lymphoscintigraphy was performed in lower limbs of patients with lipedema (n=22), and “typus rusticanus” (n=6) and controls (n=7). Their controls were not normal subjects but patients with venous insufficiency (Widmer stage II). What was original in this study was repeat lymphoscintigraphy using an identical protocol but with the injection depot administered in the subcutaneous fat of each leg, and therefore within the lipedema tissue (liposcintigraphy). Both qualitative (image assessment) and semiquantitative (speed of lymph transport) measures were recorded for analysis. The results showed no differences from the venous controls, but, somewhat surprisingly, **lymph transport was faster in the lipedema group** than in the “typus rusticanus” when studied by liposcintigraphy. Their conclusion was that epifascial lymph drainage in lipedema is not disturbed.

COMMENTARY

This study is welcome because lipedema is underdiagnosed and under-researched. Sufferers feel let down by the medical profession, particularly when dismissed as simply obese. In our experience, lipedema is undoubtedly a medical entity distinct from obesity, and almost certainly genetic in origin, given the strong dominant line of inheritance we see through the female side of families.

I am sure the authors were surprised not to see any lymphatic disturbances from the liposcintigraphy. I would have hypothesized abnormalities existed, given the frequent progression of lipedema to lymphedema (so called lipo-lymphedema or lipedema-lymphedema syndrome). It was difficult to follow clearly their quantitative measures. In the methods section the authors refer to two outcome measures: 1) Transport-Index (Ti) and 2) ilioinguinal radioactivity after 45 mins and 2 hours, but in the table of results I cannot see any reference to Ti.

The inclusion of “typus rusticanus” is interesting but I am sure that, like me, a number of readers will be thinking, what exactly is this condition? Is it a localized form of lipedema or simply fat pads over which the skin becomes cold and blue (pernioitic – like chilblains)? Do we consider this group “fat normals” or a variant of lipedema, an important distinction for interpreting the results correctly?” In summary, **an important study which raises the profile of lipedema, a neglected but important condition in women.** Unfortunately, the results do not tell us much more than we already knew, which is not a lot. Patient advocacy is increasing (info@lipedema.org) and hopefully with greater interest in, and funding of, research into the science of fat and adiposity, better understanding of lipedema will follow soon.

An Interview with Rebecca Morris of the National Lipedema Association

Rebecca Morris, the founding president of the **National Lipedema Association** (NLA), graciously agreed to an e-mail interview to share information about lipedema and the NLA.

What is lipedema?

Rebecca: Although lipedema was first identified in the United States, at the Mayo Clinic in 1940, it is not well known in this country and it is often confused with obesity or lymphedema. Patients typically are either misdiagnosed or not diagnosed at all, and most never receive appropriate medical treatment. Lipedema is a bilateral, symmetrical deposit and swelling of adipose tissue in the lower extremities following a particular pattern, from the waist to a very distinct line above the ankles; the feet and ankles are not normally affected unless lymphedema also is present. In addition to this unusual pattern, lipedema is distinctive in four ways: 1) it can be inherited; 2) it occurs almost exclusively in women; 3) it occurs in women of all sizes, from the anorexic to the very obese; and 4)

lipedemic fat generally is not mobilized by diet and exercise.

Can those with lipedema diet and exercise to get rid of the excess fat?

Rebecca: People with lipedema, even anorexics, can diet and exercise away their "normal" fat but they retain the lipedemic fat. Obese lipedema patients who undergo bariatric surgery lose their weight almost entirely from the waist up. Patients tend to gain fat in the lipedemic areas and lose it only in the non-lipedemic areas. As a result, the classic lipedemic profile, in the early stages, is a woman who looks like a size 8 from the waist up and size 16 from the waist down, with disproportionately large, column-like legs. Lipedema typically presents first at puberty, is often progressive, and can be triggered or worsen during pregnancy or at menopause. In its later stages, as the patient's lower body enlarges, lipedema can contribute to secondary lymphedema, develop in the arms and abdomen, and put patients at risk for obesity as well as other diseases and symptoms associated with increasing immobility.

How is lipedema diagnosed?

Rebecca: A lipedema diagnosis is based primarily on clinical presentation and medical history. Unfortunately, we do not yet have genetic or other markers for lipedema. In some cases, [lymphoscintigraphy](#) images of the lymphatic vessels show a flame-like pattern different from that found in lymphedema.

Do you have any estimates as to how many women are affected by lipedema?

Rebecca: Estimates are imprecise and vary widely, but many researchers and clinicians believe that a significant number of women currently classified as obese in fact have lipedema, either instead of, or in addition to, obesity.

Where does lymphedema come into the picture with lipedema?

Rebecca: As fat cells are deposited and expand, they interfere with the pathways of lymphatic vessels. This inhibits the flow of lymphatic fluid and patients can develop secondary lymphedema, usually in the lower legs. This condition is known as [lipo-lymphedema](#). At this point, the lymphedema can cause swelling in the feet and ankles.

How is lipedema treated?

Rebecca: Treatment includes Manual Lymphatic Drainage (MLD), bandaging, compression, and self-care. These components of treatment can help reduce any edema in the tissues and, in some cases, can reduce the pain associated with lipedemic fat (lipedema also is known as "painful fat syndrome"). In addition, some researchers believe that over a significant period of time, the pressure of compression will help to shrink the size, although not the number, of fat cells. For patients who also have secondary lymphedema, this treatment can help reduce the fluid volume associated with the lymphedema component.

Compression can be very problematic for many lipedema patients because of the underlying pain, and because the unusual shape of lipedemic legs means that compression garments often cause tourniquet effects at the ankles, knees and thighs. Many lipedema patients are unable to tolerate compression at all. As a result, if they also have lymphedema, they are more at risk for the side effects of uncontrolled lymphedema, including recurring cellulitis and fibrosis.

What is your goal in founding the National Lipedema Association?

Rebecca: The mission of the NLA is to educate medical providers and patients about lipedema, and to promote and support research that benefits people with lipedema. Because lipedema is not well known, we want to educate doctors, nurses, and other medical providers so that they can properly diagnose lipedema and refer patients for appropriate treatment. We are working on new compression options specifically for lipedema, so that therapists have more tools for treating lipedema patients. We are working with lipedema researchers to identify appropriate patients for studies and generally to facilitate their work. We will promote lipedema research specifically, and more generally research in lymphatic and metabolic disorders that ultimately will benefit lipedema patients.

Our web site at www.lipedema.org will launch in the next few months, and will include educational materials and news about lipedema, a medical literature database, patient and medical provider registries, and links to resources for clinicians, therapists and patients.

How can those who are interested become active in the National Lipedema Association?

Rebecca: You can contact us by e-mail at info@lipedema.org to join our mailing list. Please tell us if you have particular needs, and we will try to connect you with the right resources. If you are a doctor or therapist having difficulty treating a patient, we will refer you to information sources and/or refer you to other providers who have had similar problems. Please also tell your patients about the NLA.

What kind of help would be most valuable to the NLA and its members?

Rebecca: If you are a patient and other members of your family also have lipedema, please let us know; you may be a candidate to participate in one of the ongoing research studies. We need volunteers to help with a wide array of projects, and we'd love to hear from you about your interests. And finally, of course, we need money to help fuel our dream of finding treatments and eventually a cure for lipedema. All donations are tax-exempt.

The National Lipedema Association mailing address is 27 Freeman Street, Arlington, MA 02474.

Rebecca can be reached by e-mail at morris@lipedema.org

Note: To learn more about how lipedema and lymphedema compare, see [Lipedema and Lymphedema Compared](#).

Arikel: Weight Gain May Not Be Obesity in Women by HealthNewsDigest.com

An obesity epidemic continues to sweep the country and efforts are increasing to fight the growing number of people affected. Health care providers have consistently endorsed healthy eating and regular exercise as a way to combat obesity and weight gain. But for a significant number of women across the country, dieting and exercise will not make a difference. That's because they are not suffering from obesity. **They have a lymphatic and metabolic disorder called lipedema.** **Lipedema** involves the extra deposit and expansion of fat cells in a distinct pattern on the body, usually from just below the waist to right above the ankles. In some cases, the arms and torso can be affected. A person with lipedema can appear quite skinny from the waist up, but obese from the waist down. The fat distribution occurs on both sides of the body in a similar fashion. Lipedema predominantly affects women. It can be inherited and can occur in women of any size.

"It is most likely a hormonal disturbance because men don't typically suffer from lipedema," said Guenter Klose, a pioneering therapist who helped establish treatments in the United States for lymphatic diseases, especially lymphedema. Lymphedema is a swelling of a body part and the result of abnormal accumulation of lymph fluid. The condition can develop in untreated lipedema patients, and at that point the disease is known **lipo-lymphedema**. Based in Red Bank, N.J., Klose is a National Lipedema Association scientific advisory board member.

Lipedema typically manifests at puberty, but it can show up or worsen after a pregnancy, after gynecological surgery or at the start of menopause. As the disease progresses, patients with lipedema can experience a host of problems. Patients can experience painful swelling, bruising, infections, and fibrosis, which is the formation of scar-like tissue. Recognizing lipedema is not easy in the early stages, especially when patients are not obese. As the disease progresses and patients become larger, they are often labeled obese, going years without a proper diagnosis.

"I found out I had lipedema in much the same way that many lipedema patients do," said Rebecca Morris, founder and president of the National Lipedema Association in Arlington, Mass. "I recognized the symptoms of lymphedema in my legs. In 2002, for the third time and at my insistence, I was referred for lymphedema therapy." It was the therapist treating Morris' lymphedema who concluded she had had lipedema, an opinion later confirmed by physician specialist. Neither Morris nor her primary care physician knew what lipedema was.

Unlike the fat associated with obesity, lipedemic fat cannot be exercised away. In addition, this fat

tissue does not respond or reduce with diet, Klose said. As a result, undiagnosed patients end up frustrated and confused. There is currently no cure for lipedema and the limited treatments available focus on alleviating symptoms. Compression garments and manual lymphatic drainage can help reduce pressure sensitivity. The results are gradual and it requires a lot of patience and dedication to the program by the patient. The National Lipedema Association is working to improve care for the condition by promoting research, as well as better recognition of the condition by both health care professionals and patients.

From the LYMPHOEDEMA ASSOCIATION OF AUSTRALIA: Recognition, Diagnosis and Treatment of Lipodema

Lipedema is a chronic disease of complex causes, many of which we understand little about. These include hormonal imbalance, an inability to metabolise exudate from blood vessels so that those proteins and cells that would normally be metabolised and returned to the circulation are deposited as adipose tissue in the subcutaneous tissue. The blood vessels themselves are affected, venous stasis and vasoconstriction occur and return is diminished especially at the subcutaneous level. This causes arterial constriction which accounts for the cold and often pale skin and leads to an increased lymphatic load(1). **The condition worsens over years as tissue channels become progressively narrowed until the condition of a secondary lymphoedema, overlying the original lipodema, may lead to a situation where the patient may be either wheel-chair bound or bedridden. Weight gains can be up to or greater than 250 kgs. At this stage infections and intractable ulcers (or ones that necessitate skin grafts when lack of oxygenation to the skin causes problems with healing) which can be due to the simplest injury e.g. careless donning of a compression garment or other minor trauma, occur with an even higher frequency.**

This condition occurs predominantly in women, and can in some cases be familial; the rare cases of men with lipodema always seem to include a hormonal imbalance which should be treated if possible. The macrophages themselves become overloaded and cease to play an active role in protein proteolysis and look like fat cells.

Lipedema is often misdiagnosed as obesity in its earlier stages but the symptoms are clear and distinctly recognisable clinically from this. In its later stages it may be more difficult to distinguish from lymphoedema, although the case history and distribution of excessive tissue should provide an indication. The overlying condition of lymphoedema may occur in the later stages. Lipodema can occur in the legs, buttocks and also, but not necessarily, in the arms. It does not involve either the feet or hands until the onset of lymphoedema. The mean age of diagnosis is approximately 35-36 years but

it usually starts at puberty. Symptoms of onset, however, can start in childhood, and may be clinically detectable in adolescence. Cellulite, which is a very mild form of lipodema, usually occurs towards or after menopause. It has been suggested that a mixture of primary lymphoedema as well as lipodema can occur in some cases.

Differential Diagnosis

Lipedema

- There is symmetrical bilateral enlargement of limbs, both in legs (with buttocks involved) or in both legs and arms, but with the obvious enlargement excluding the feet and hands, until the later stages. Enlargement is a gradual but continuous process.
- There is no pitting with pressure. The tissue feels more like "rubber", and is not as hard and fibrotic as in a grade II lymphoedema. It does not, in the early stages, reduce with elevation.
- There is pain on pressure, especially in the medial aspect of the thigh and the base of the spine. As the disease progresses, pain is often caused by the lightest of touches to the skin, particularly later in the day. Pain is also caused by "self pressure" e.g. crossing the legs or sitting with pressure on the spine. The abdomen may also be painful to pressure.
- Stemmer's sign is negative; i.e. a skin fold test done on the second toe. If it comes up as a thin fold test when "pinched", no lymphoedema is present. If it is a "lump" this indicates lymphoedema.
- Superficial capillaries are easily damaged i.e. the limb bruises easily.
- Skin temperature is lowered. Hands may feel clammy (damp), but limbs are cold. General nourishment of the skin is also affected and may cause "patchy" skin, dry in one place, oily in others in the early stages. Skin elasticity is reduced and it usually has an "orange peel" appearance.
- "Pins and needles" are common and movement seems to alleviate these to a large extent. A feeling of dizziness may be present. There seems to be a reduction of venous return in the legs when standing which can lead to fainting; this may be prevented by walking.
- There is little or no loss of weight with rigorous diet. Many of these patients have eaten low calorie diets for many years. In some cases their stomachs have been stapled because of misdiagnosis. In some of these cases, this seems to have led to the onset of stomach cancer. It is not the answer to the problem! Obesity, caused by overeating, does respond to a proper dietary regime; lipodema does not.
- Joint pains (especially in knees) are common.

Infection of the limb, either bacterial or mycotic is not normally a problem.

Plantar support is reduced i.e. people have fallen arches.

The shape of lipodema may vary, from an inverted "pear" shape (like a classical Greek column) to a more bulbous shape from the ankles upward. (Figs. 1-2.) This also usually involves the buttocks.

Lymphoscintigraphy i.e. time of clearance of a radio-tracer injected into the feet to the inguinal nodes, is normal.

Secondary Lymphoedema Accompanying by Lipodema in the later stages.

Stemmer's sign becomes positive.

Pressure will cause pitting, and there may be a small reduction with elevation.

Folds of skin will further enlarge and feet will swell (Fig. 4.). If arms are affected hands also will swell.

If the top of the body is affected the shoulders, thoracic and neck area may be affected as well.

Infection may become a problem.

Diagnosis can normally be achieved by the taking of a careful case history and clinical observation (see above). In the later stages lymphoscintigraphy may clarify this, but the picture is so different from primary lymphoedema that this should seldom be necessary.

Psychological Problems

All of these patients present with a variety of these problems ranging from lack of self-confidence to lack of confidence in their medical or health workers, often because of misdiagnosis and lack of sympathy, and then to real depression and anxiety and because of their appearance and the lack of understanding of the condition, particularly as their mobility decreases. The whole problem, of course, becomes worse if the onset of lymphoedema further exacerbates the condition.

They are "blamed" for being overweight, told they eat too much or are "cheating" on their prescribed diets. If they are hospitalised for a weight loss program when the situation becomes very serious and they don't lose weight, they are often met by the comment "I am surprised" by their health care professionals and are summarily dismissed as "patients for whom nothing can be done" or "we don't know what is wrong with you" or "you'll just have to live with it". This is not helpful to the patient who should be made aware that **the condition is a genetic abnormality and that their obesity is not their fault**. Of course, up to a point dieting can help but it will never cure this condition. They obviously, and for good reason, become discouraged and dismayed by their problems, which seem not even to be recognised. **When lymphoedema occurs on top of the lipoedema this is a situation which is almost a problem that is so great for them (and again often undiagnosed as such) that they need to be very strong people to cope with it.** Sadly, many are not able to do this. Psychological counselling can be helpful; for this poorly understood condition it is seldom offered. Invalid Pensions are not the answer for those that have, until they could not, lead an active and productive life. In many centres in Australia and I am sure worldwide, these patients are turned away from treatment centres (for lymphoedema) as untreatable cases. In some cases they resort to surgery in a final effort to improve their condition. The result of some of these operations (including liposuction and limb reduction) are so appalling that they have to be seen to be believed.

Treatment

Lipodema can be treated and reduced with careful massage to the normal nodal groups after the truncal areas have been precleared i.e. the superficial inguinal and axillary nodes, then gentle superficial drainage towards these. and compression applied to the legs in the form of bandaging as garments. Although not as easy to treat as is lymphoedema, considerable reduction, easing of pain and

improvement in mobility, can be of huge physical and psychological benefit to the patient. Compression bandaging is tolerable, especially after a few days of massage. The overlying lymphoedema, if present, can be greatly reduced. The improved mobility will increase the ability to exercise which will help the calf muscles pump and increase venous and lymphatic return. After the initial decongestion by manual drainage permanent compression causes a significant reduction in adipose tissue and also has a positive influence on the disturbed veno-arterial response.



Benzo-pyrones seem to help this condition considerably, presumably by their stimulation of macrophage numbers and activity. Many patients have reported a considerable weight gain when coumarin became unavailable in Australia. Interestingly, the Italian product Cellasene[®] which is recommended for cellulite, contains benzo-pyrones and other plant extracts that work in a similar way to benzo-pyrones, so despite medical scepticism, this may help in these conditions. Unfortunately the cost of these and other available benzo-pyrones are too high for many people who would benefit from them.

The only diet which may help is a very low protein only diet (250 mg per day) (and nothing else, except, of course, water), which will put the body into a state of ketosis where some of the excess fat may be metabolised. However this usually results in weight loss in already lean areas e.g. the waist and often the upper body. Operative procedures do not attack the cause of the problem. Careful liposuction may produce immediate reduction but considering the destruction of tissue it causes, long term results have not been clinically proven. Other reduction operations are contraindicated. Pumps are normally intolerable because of the pain they cause, and there is no published evidence of them ever being successful in this condition.

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More about Lipedema

The term lipedema was first used by Allen and Hines (1940) to describe a symmetrical "swelling" of both legs, extending from the hips to the ankles, caused by deposits of subcutaneous adipose (fatty) tissue. The underlying etiology of these fat deposits remains unknown.

While lipedema is not a disorder of the lymphatic system per se, it is frequently confused with bilateral lower extremity lymphedema.

It occurs almost exclusively in women and may have an associated family history (20 per cent of cases) and is usually accompanied by hormonal disorders as well (Strossenreuther, 1999). If present in a man, it is accompanied by massive hormonal disorder.

Fat in the lower extremities extends to the malleoli (ankle bones), often with flaps of tissue hanging over the foot. The feet are not affected; occasionally, lipedema is found in the arms. Typically, there are also fatty bulges in the medial proximal thigh and the medial distal thigh, just above the knee. Clinically, the affected individuals complain of pitting edema as the day progresses, which is relieved by prolonged elevation of the leg(s) overnight (Rank and Wong, 1966; Rudkin and Miller, 1994; Casley-Smith, 1997).

Stages of Lipedema.

In Stage I, the skin is still soft and regular, but nodular changes can be felt upon palpation (see photo 1).



There are no color changes in the skin and the subcutaneous tissues have a spongy feel, like a soft rubber doll. In Stage II, the subcutaneous tissue becomes more nodular and tough. Large fatty lobules begin to form on the medial distal and proximal thigh and medial and lateral ankles just above the malleoli (see photo 2). Pitting edema is



common, increasing as the day progresses

The individual may report hypersensitivity over the anterior tibial (shin) area. Skin color changes occur in the lower leg, indicative of secondary lymphedema, which often occurs in later stage lipedema.

Pathophysiology of Lipedema (Strossenreuther, 1999).

There are many histological and physiological changes that occur in lipedema. There is a decrease in the elasticity of the skin and

| underlying connective tissue. The basement membrane of blood vessels is thickened and there are disturbances in vasomotion. There is decreased vascular resistance, increased skin perfusion, and increased capillary filtration. There is increased venous/blood capillary pressure causing increased ultrafiltration. These vascular changes combined with the decreased efficiency of the calf muscle

pump, result in both the dependent pitting edema seen in Stage I, as well as the the secondary lymphedema that often complicates lipedema in its later stages. Histological changes seen in lipedema include a thinning of the epidermal layer, thickening of the subcutaneous tissue layer, fibrosis of arterioles, tearing of elastic fibers, dilated venules and capillaries, and hypertrophy and hyperplasia of fat cells. Clinical studies show that there is enlargement of the pre-lymphatic channels (Stoberl et al., 1986) as well as defects in capillary perfusion (Weinert and Leeman, 1991). Some authors have reported no alteration in lymphatic transport (Brautigam et al., 1998) while others (Bilancini et al., 1995) have reported decreased lymph outflow in those individuals with lipedema. Foldi and Foldi (1993) reported an increase in fat cell growth during lymphostasis.

Medical Management

Diagnosis. The diagnosis of lipedema is difficult if the clinician is unfamiliar with this condition. Often, these people are told that they are "fat" and should just lose weight to resolve the problem. For reasons still unknown, the fatty tissue accompanying this condition cannot be significantly decreased by diet. It is not uncommon for a diagnosis of primary lymphedema to be made. This results in frustration for the person who then seeks out lymphedema therapy with poor results.

There are several significant clinical differences between lipedema and bilateral primary lymphedema. The feet are not involved in lipedema; while they are edematous with a positive Stemmer's sign in lymphedema, Stemmer's sign is negative in lipedema. The "swelling" in lipedema is symmetrical, while in primary lymphedema usually one limb is more involved than the other. The subcutaneous tissues feel rubbery in lipedema. In advanced Stage II lymphedema, there is significant subcutaneous fibrosis, which feels firmer than lipedema. While there have been reported incidences of cellulitis in Stage II lipedema (usually with a component of lymphedema as well), the frequency of cellulitis in Stage II lymphedema is much higher. The time of onset of the "swelling" in lipedema is usually around puberty and 90 per cent of these cases have accompanying diagnoses of hormonal disturbance (thyroid, pituitary, or ovarian). This is usually not the case with primary lymphedema.

A lymphoscintigram may be helpful to differentiate between lymphedema and lipedema, however, there can be conflicting results as lymphedema often occurs to some degree in the later stages of lipedema, probably due to impairment of lymph flow caused by the pressure of fatty tissue. In fact,

there are clinical cases of bilateral lower extremity lymphedema in the morbidly obese individual; the onset of the lymphedema occurs after body weight exceeds 350-400 pounds. It is plausible to suspect that the pressure of a large apron of abdominal fat can effectively block lymph flow through the inguinal area causing the lymphedema but there is a difference between these cases and lipedema because obesity does not cause lipedema. Lipedema is caused by a hormonal imbalance resulting in excessive deposition of adipose tissue, most often in the lower extremities (see Figs. 12-21; 12-22) although it can occur in the upper extremities as well.

Treatment and Prognosis.

There is no effective medical treatment for lipedema and the prognosis is guarded; however, significant functional improvements are possible with good program compliance and therapy intervention. Medical management involves treating the hormonal disturbance as effectively as possible and providing nutritional guidance to avoid additional weight gain. Many of these individuals have endured years of ridicule because of their physical appearance and become recluses in their homes, further limiting their activity level. As lipedema progresses and the hypersensitivity increases, they feel less inclined to walk or exercise because of the pain. They inevitably gain more weight due to the inactivity and depression, often finding food their only comfort.

The primary goal of therapy intervention in the person with lipedema is symptomatic relief and realistic improvement of trunk and lower extremity function. Application of the combined lymphedema treatments has shown some success in relieving the pain and hypersensitivity in the lower legs and improving general mobility. Usually, a lower level of compression is needed to support a lipedematous limb, compared to a lymphedematous limb of the same size and girth. This guideline applies to the compression garments as well. These individuals often require more padding under the compression bandages, particularly in the anterior tibial area. They do not tolerate the heavier, denser compression fabrics and usually require a lower grade compression garment than someone with uncomplicated lymphedema. The therapist must remember, however, that later stage lipedema is often accompanied by lymphedema as well, and the treatment and management must take that factor into consideration when recommending exercise and garments.

The main goals of intervention are to decrease pain and hypersensitivity, to decrease the lymphedematous component of the disease, and to assist the individual in maintaining and/or reducing adipose tissue through exercise and nutritional guidance. The compression garments can help to decrease the adipose tissue with exercise and weight loss. The most difficult task is fitting the compression garments. They must be custom made due to the large size of the individual and are often

uncomfortable at the waist, particularly when sitting. Making the radical change in daily activity level is most challenging for these individuals. Providing continued support and encouragement is important.

How to distinguish lymphedema from lipedema.

A very good article was published in the April edition of Consultant (2001) 41, 613. The figure demonstrating lipedema is from that article.



Lymphedema and lipedema are often confused. Lymphedema is due to increased lymphatic pressure with accumulation of edema in the subcutaneous tissue. Over time this results in firming or hardness of the tissues that is characterized by fibrosis. In contrast, lipedema results from the deposition of excess fat in the subcutaneous tissues but does not involve lymphatic hypertension or abnormal lymphatic vessels. The excess fat is normal in appearance under the microscope and there is generally no abnormalities of the lymphatic channels. In addition, there is no abnormal accumulation of excess edema or fibrosis in lipedema.

There are several features about lipedema that distinguish it from lymphedema. One of the most notable differences is the fact that the feet are generally not involved in lipedema. The excess accumulation of subcutaneous fat can involve the entire leg but will generally stop at the ankle, leaving a characteristic ring at the base of the ankle where the lipedema stops. Another difference is the fact that the excess fat is generally symmetric so that both legs are involved equally. In many patients, only the lower extremities and the buttocks are involved, with no excess accumulation of fat in the arms, chest or abdomen. Chronic venous insufficiency can cause a similar appearance; however, chronic venous insufficiency results in swelling of the feet and the accumulation of subcutaneous fluid. The pitting edema seen in lymphedema and in edema due to congestive heart failure is generally not seen in lipedema. This is why leg elevation can be helpful to many patients with venous stasis and to some patients with lymphedema, but is rarely helpful for patients with lipedema. The excess fluid seen in venous insufficiency and lymphedema causes darkening and fibrosis of the skin over time. These skin changes are not seen in lipedema. Congestive heart failure can cause swelling in the legs; however, lipedema is characteristically seen in women and generally starts during adolescence. These patients do not have heart failure. Ulcers and recurrent infections are commonly observed in venous stasis and

lymphedema respectively, but are rare in lipedema.

Lipedema generally starts slowly during adolescence and progressively worsens over time, especially in patients who gain significant amounts of excess weight. Dieting can result in a normal appearance in the upper body but persistently enlarged legs. Diet control can be helpful in the management of lipedema since it appears that excess fat preferentially accumulates in the lower extremities. Patients with lipedema often have a history family members with disproportionately large legs.

The treatment for lipedema is generally diet control. Excess weight will preferentially accumulate in the lower extremities. However, even strict dietary measures may not result full resolution of the lower extremity accumulation of lipid. Elevation and compression have modest impact since there is no vascular compromise and no interstitial fluid that needs to be removed. Some efforts have been made to treat lipedema with surgical removal of the excess fat. It is too early to determine the long-term effects of these surgical treatments.

Lipoedema Australië: **Broadcast ABC online: 6.30pm on 7/5/2002**

Presented by Dr Norman Swan

Lipoedema is an abnormal accumulation of fat cells which usually occurs in the legs and almost always in women. Unlike obesity the woman's legs increase in size but not their feet, and the skin is often painful to touch and easily bruised. If there is only a small amount of lipoedema it does not create a health problem but large accumulations of fat can block the lymphatic system and cause lymphoedema (an accumulation of fluid). Unfortunately there are no effective treatments as yet but the Lymphoedema Assessment Clinic at Flinders Medical Centre in Adelaide is currently testing new treatments.

NORMAN SWAN: Cellulite is a word that many women dread, something that was invented by the cosmetic industry to make money out of women's fears.

But there is another kind of fat involving women's legs that can cause serious problems. And they've been trying to find solutions for it in Adelaide.

I went to see what they came up with. A few years ago it would have been unthinkable for Margie Broomhead to show her legs on national television.

And although she is a keen swimmer, she was even too embarrassed to show them at the beach.

MARGIE BROOMHEAD, PATIENT: I reached the stage where I thought -- "Blow this.

It's something I can't do anything about." I'll go down in bathers."

I thoroughly enjoyed it but I could still see people looking at me and you know, "Ooh, look at that!" and

I didn't do it any more.

NORMAN SWAN: As a young woman, Margie had no problem keeping her slim figure but after the birth of her daughter, she needed a series of abdominal operations and she began to put on alarming amounts of weight.

MARGIE BROOMHEAD: The gynie just said "You've got to have, this and you've got to have that, you've got to have -- " and it was endless but nobody was doing anything about me putting on weight. He did put me on a diet, umpteen other doctors put me on a diet, Every doctor I met put me on a diet.

(Laughs) We got nowhere.

NORMAN SWAN: Margie's problem wasn't her eating. It was lipodema. Lipodema is an abnormal accumulation of fat, almost always in the legs and almost always in women. It's usually inherited, so Margie's operations weren't the cause. In fact, it usually starts to occur when you put on a bit of weight. But as opposed to general obesity, the weight accumulates, as I said, in the legs and sometimes the arms and dieting won't shift it.

PROFESSOR NEIL PILLER, FLINDERS MEDICAL CENTRE: The interesting thing with this group of people is that they don't seem to respond to diet.

In other words, they can be put on a low-calorie diet and nothing much will happen, they won't lose the weight. They may lose the weight around here on their chest area or their tummy area but their legs will stay the same.

NORMAN SWAN: Researchers at the Flinders Medical Centre in SA became interested in lipodema because it can cause lymphoedema, a pooling of lymphatic fluid in the legs which makes them swell even more.

PROFESSOR NEIL PILLER: In a mild form it's OK, but if you get a severe form then the individual fat cells become so large and so significant that they begin to impact on the lymphatic system.

NORMAN SWAN: Lipodema is poorly recognized and commonly dismissed as obesity.

To the frustration of women with lipodema, medical science has few solutions.

PROFESSOR NEIL PILLER: I must say with lipodemas, they're very, very difficult to manage.

Once you've got them, what you can do is minimise the lymphatic component of them.

It's very hard to manage the fatty component of them.

NORMAN SWAN: But, the news is better for women like Margie whose lipodema is causing lymphatic fluid retention.

Lasers and massage machines are improving the treatment for lymphoedema, significantly reducing the pain and the size of their legs.

MARGIE BROOMHEAD: I still haven't got anywhere near Betty Grable's legs.

PROFESSOR NEIL PILLER: We're working on it.

How does lipoedema characteristic differ from lymphoedema?

What is lipoedema? Allan and Hines first described Lipoedema in 1940 as a bilateral enlargement of the legs thought to be due to abnormal deposition of subcutaneous fat and the accumulation of fluid in the lower legs. They also classified it as 'painful fat syndrome'. It was not until 1949 that Wold et al would define diagnostic criteria for lipoedema that included bilateral, symmetrical leg swelling **excluding the feet**, which remain normal in size; minimal pitting oedema; pain and bruising in the swollen areas and large legs, thighs and buttocks despite dieting. In addition, the condition occurs almost exclusively in females and is normally first noticed at puberty or pregnancy.

Unfortunately, lipoedema is often not diagnosed and can be mistaken for several conditions including lymphoedema or obesity. Lipoedema can manifest with both physical and psychological problems including: discomfort at sites of swelling, spontaneous bruising and tenderness as well as a hatred for the disproportionally large legs while Western culture values the perception of slender legs.

What is lymphoedema?

The function of the lymphatics is to clear protein and water from the tissues. Fluid accumulation can be due to the absence, damage to, or obstruction of lymphatic vessels affecting the transporting capacity of the system. When the fluid formation is increased to a point that it overwhelms the capacity of the lymphatics absorptive system, oedema (swelling) occurs.

Lymphoedema of the legs tends to occur after puberty (but can occur at any age) with foot and ankle swelling. It can affect both males and females. In the early stages of chronic (long-term) lymphoedema, the swelling can be reversible. Pitting of the skin is invariably present. Swelling can disappear after a night's rest, although not in established lymphoedema. Yet, if this swelling continues and is left untreated, it will continue to increase and the skin may become hardened, dry and scaly in appearance.

The increase in weight can cause joint problems, leading to a reduction in mobility and pain occurring in the affected limbs. As a result of the swelling and altered local immunity, cellulitis may occur. This manifests as hot, red skin that can break down because of blistering. The individual may become systemically unwell and experience flu-like symptoms. A prescribed course of antibiotics as soon as possible is required. If very unwell, the patient may require intravenous antibiotics in hospital. Multiple episodes of cellulitis can occur leading to treatment using long term prophylactic

antibiotics.

To further explain lipoedema, it is necessary to compare this condition to lymphoedema.

Lymphoedema is usually asymmetrical and can be either acquired (through injury to the limb or tumours) or congenital (hereditary). Lipoedema on the other hand, is seen as the symmetrical enlargement of both lower limbs, beginning at the ankle and extending proximally as far as the waist and appears to be hereditary. The table below further highlights the obvious differences.

Characteristic	Lipoedema	Lymphoedema
Sex	females only	males & females
Age of onset	puberty	usually pubertal
Family history	around 40% of cases	around 20% of cases
	(Harwood et al 1996)	(Harwood et al 1996)
Obesity	yes	variable
Symmetry	usually symmetrical	always symmetrical
Swollen feet	never	usually
Skin consistency	normal or thinner	thicker & firmer
Pitting of skin	usually absent	always pits
Easy bruising	often	no increase
Pain & discomfort	often	infrequent
Tenderness	often	infrequent
Effect of dieting	little effect on legs	even loss from trunk & legs

The sparing of the feet causes a 'bracelet effect' at the ankle. Unlike lymphoedema, lipoedema does not appear to cause skin thickening. The individual will often complain of extreme aching and tenderness within the affected limbs, especially around the knees due to the extra weight. Pain may be much more

of a feature than with lymphoedema.

How does lipoedema differ from obesity?

Body fat is made up of adipose tissue that is important as a store of energy. This fat can be mobilised quickly in response to metabolic demands. Obesity can be thought of as excess body fat. This can cause health problems including; high blood pressure and diabetes. If an obese individual attempts to diet, the weight will be lost uniformly from all over the body. **Yet, an individual with lipoedema will lose weight preferentially from upper body and face.** The reason for this at present is not known.

What causes the fluid retention to occur in lipoedema?

Whilst fluid retention appears to occur to a significant degree with lymphoedema, it has been recognised with lipoedema that in the early stages the oedema may be minimal but over time this will increase and an individual may present with lipoedema and lymphoedema. So both conditions may coexist.

Treatment

Dieting and Exercise

This condition is often misdiagnosed and treatment also. Individuals are advised to diet and lose the excess weight. This can in the short-term, help if the individual is obese. If the individual is not overweight and just disproportionately large from the waist down, this can potentially lead to a state of anorexia. The individual will attempt to lose weight, unfortunately, due to the nature of the condition, the individual will remain large from the waist down, whilst losing the weight from the upper body and face. This can exacerbate the disproportionate nature of the condition, leading to increased feelings of depression and disturbed body image.

Exercise is essential not just for 'burning fat' but also for enhancing any 'sluggish' lymph drainage, which likely co-exists. **The best exercise to undertake is water aerobics.** This will support the joints whilst allowing resistance to occur which will increase your heart rate. If this is not appropriate then walking can be of benefit either on a treadmill or outside. However, this may put added stress onto already painful knee joints.

Diuretics

Alternatively, diuretics are prescribed, in the belief that the swelling is caused by fluid retention, but

very little, if any, benefit will be gained.

Hosiery

Perhaps the most successful treatment currently available is the use of surgical support stockings in combination with movement and exercise. These stockings, whilst expensive, can usually be obtained via the GP. The benefits of stockings include; helping redefine the shape of the limb and encouraging improved venous and lymphatic drainage helping to prevent aching, providing exercise is pursued.

Diagnostic Tests

Lymphoscintigraphy can distinguish swelling due to lymphoedema from lipoedema. The test involves injecting a very small amount of radioactive material between the toes of the affected limbs. The radioactive tracer is monitored as it is taken up by the lymph glands. If the individual has lymphoedema, this test usually demonstrates that the lymphatic collecting channels are abnormal. In lipoedema, lymph drainage routes are patent and functional.

Liposuction

Liposuction is a commonly undertaken procedure for excess fat (and even in certain cases of lymphoedema). It is best used for localised areas and not over large regions such as a limb. The likelihood of achieving an even effect (liposculpture) is small and cosmetically there may be no improvement.

Current Research

Treatment is still largely unavailable to many individuals with lipoedema, through a lack of understanding as to the causes of the condition. Research continues to play an important part in helping to find a cause. The Lipoedema Study Group is undertaking one such study at St George's Hospital Medical School in London. Through the use of blood samples given by individuals with lipoedema, this study aims to identify genes that can predispose an individual to develop lipoedema within their lifetime. Currently this study is in the early stages, but it is anticipated over the next few years enough families with one or more affected relatives will be located to provide the necessary blood samples for genetic analysis. Individuals can either be referred to the study by their GP or can contact Miss Pip Sharpe, Research Nurse.

It is hoped that the study will help to bring further awareness of lipoedema and help individuals with the condition to cope better both physically and psychologically with its effects.

Conclusion

In conclusion, it has been shown how hard it is to make an accurate diagnosis of lipoedema. Often, individuals will present with a combination of signs and symptoms, which may overlap with lymphoedema, making a straightforward diagnosis very difficult. The key factor to come out of the research so far has been that individuals with a diagnosis of lipoedema need to have both physical and psychological support to help them overcome the mental anguish, which accompanies the abnormally large limbs. These individuals need to know that they are not 'going mad' and that they are not primarily obese, which is very often definitely not the case.

Lipedema – what do we know? by

Professor Horst Weissleder

Allen and Hines described in 1940 (1) “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.”

Since then most of the articles dealing with lipedema have been published in Europe.

Definition

Lipedema (painful fat syndrome) can be defined as a chronic disease that occurs in female patients and is characterized by bilateral, symmetrical fatty tissue augmentation mainly in the hip region and upper and lower leg combined with a tendency to orthostatic edema. In male patients lipedema is extremely rare (2).

Morphology

Fat cells have a spherical shape and like any other cells contain fat deposits covered by a micro filament-reinforced cell membrane. Groups of fat cells form lobes which are surrounded by fibrous tissue. The septa between the lobes contain blood and lymph vessels and nerves. Fatty tissue has an excellent blood supply but fat cell-associated lymph capillaries are not present. Lipedema is likely triggered by a microangiopathy with an increased fragility of the blood capillaries. The increased capillary permeability then leads to a protein-rich intercellular edema. In subsequent stages, inflammation sets in leading to perivascular fibrosis, a few areas of fatty tissue necrosis, oil cysts and an increase in the number of the macrophages. Prominent mast cell recruitment and other inflammatory effects eventually lead to interstitial fibrosis (4).

Pathogenesis

Right now, the pathogenesis of lipedema and other types of fatty tissue enlargement (lipohypertrophy and obesity) is still unclear. According to the literature, the regulation of the fat metabolism seems to

be a very complex process. There might be interaction with the nervous system, different hormones and the microcirculation (3). Genetic factors may play a role too. Details regarding the connections of the different systems and the possible influence of drugs have yet to be clarified. In addition, it is not known exactly if the increase of fatty tissue is caused by hypertrophy or hyperplasia of the fat cells (adipocytes). An increased blood flow and an increased angiogenicity support fat reduction. In contrast a reduced blood flow seems to increase the storage of fat. The same may be true in cases of a reduced lymph flow.

Diagnosis

Basic diagnostic procedures including medical history, inspection and palpation and additional laboratory tests provide the basis for further examinations that might be necessary to finally assess the disease. In most cases, lipedema (symmetrical, pillar like volume augmentation) develops during puberty or some years later. Heavy hips and thighs are obvious signs. Women with lipedema frequently complain about pain by compression independent of the extent of fatty tissue proliferation. Small injuries that cause no macroscopic lesions in healthy people can result in hematoma due to an increased fragility of the blood vessel wall. When the lymphatic system is not damaged the feet are normal and the Stemmer sign negative. Lipedema is frequently seen in female relatives (e.g. mother, grandmother, sisters).

Based on inspection and palpation lipedema can be graded into three stages:

Stage I: has a normal skin surface. The subcutaneous fatty tissue has a soft consistency but multiple small nodules can be palpated. This stage can last for several years.

Stage II: the skin surface becomes uneven and harder due to the increasing nodular structure (big nodules) of the subcutaneous fatty tissue (liposclerosis).

Stage III: is characterized by lobular deformation due to increased fatty tissue. The palpable nodules varying in size from a walnut up to a fist and can be distinguished from the surrounding tissue by palpation. When the skin is pushed together, the so called peau d'orange or mattress phenomenon can be demonstrated.

Differential diagnosis

The most common mistake in the assessment of lipedema is diagnosis as lymphedema. The false diagnosis is usually based on the fact that the entire set of lipedema symptoms are often not known and cannot be found in many textbooks. Therefore, massive lipedematous volume increases in the legs are commonly diagnosed as obesity or lymphostatic elephantiasis (7, 8). On the other hand lipedema can be seen quite often combined with other diseases e.g. obesity, chronic venous insufficiency and lymphedema. With lipo-lymphedema, the tissue is indurated and pretibial indentations can be made. Contrary to simple lipedema, the regions of the ankle and the dorsal foot are edematous. Natural skin creases are deepened and a positive Stemmer sign confirms damage of the lymphatic system (7, 8).

Treatment

Up till now lipedema could only be treated using conservative methods with complex physical therapy and exercises. By this, a reduction of edema and a decrease or elimination of tension and pain could be reached. Nowadays the increased fat volume can be removed by surgical therapy with liposuction in tumescent local anesthesia. However, an existing lymphangiopathy must be considered as a contraindication. Liposuction is the most frequently used cosmetic procedure not only in the United States but also in Germany. Cosmetic surgery is lucrative and is increasingly being performed by non-plastic surgeons and non-physicians, some of whom have little more experience than a weekend seminar. The public perception of this cosmetic procedure as minor cosmetic surgery fails to consider the possibility that major complications may result from this which could cause fatal outcome according to recent publications. Therefore it is strongly recommended that liposuction in lipedema be performed only in specialized centers using modern techniques (5, 6). Finally, it should be mentioned that lipedema is not caused by excessive consumption of calories; hence calorie reduction will not be beneficial. Dietary measures are advised only with obesity.

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It is perfect not to be perfect

An elderly Chinese woman had two large pots, each hung on the ends of a pole which she carried across her neck. One of the pots had a crack in it while the other pot was perfect and always delivered a full portion of water. At the end of the long walk from the stream to the house, the cracked pot arrived only half full.

For a full two years this went on daily, with the woman bringing home only one and a half pots of water. Of course, the perfect pot was proud of its accomplishments. But the poor cracked pot was ashamed of its own imperfection, and miserable that it could only do half of what it had been made to do.

After 2 years of what it perceived to be bitter failure, it spoke to the woman one day by the stream. "I am ashamed of myself, because this crack in my side causes water to leak out all the way back to your house." The old woman smiled, "Did you notice that there are flowers on your side of the path, but not on the other pot's side? That's because I have always known about your flaw, so I planted flower seeds on your side of the path, and every day while we walk back, you water them." "For two years I have been able to pick these beautiful flowers to decorate the table. Without you being just the way you are, there would not be this beauty to grace the house."

Each of us has our own unique flaw. But it's the cracks and flaws we each have that make our lives together so very interesting and rewarding. You've just got to take each person for what they are and look for the good in them.

To all of my crackpot friends, have a great day and remember to "smell the flowers"!!!!

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