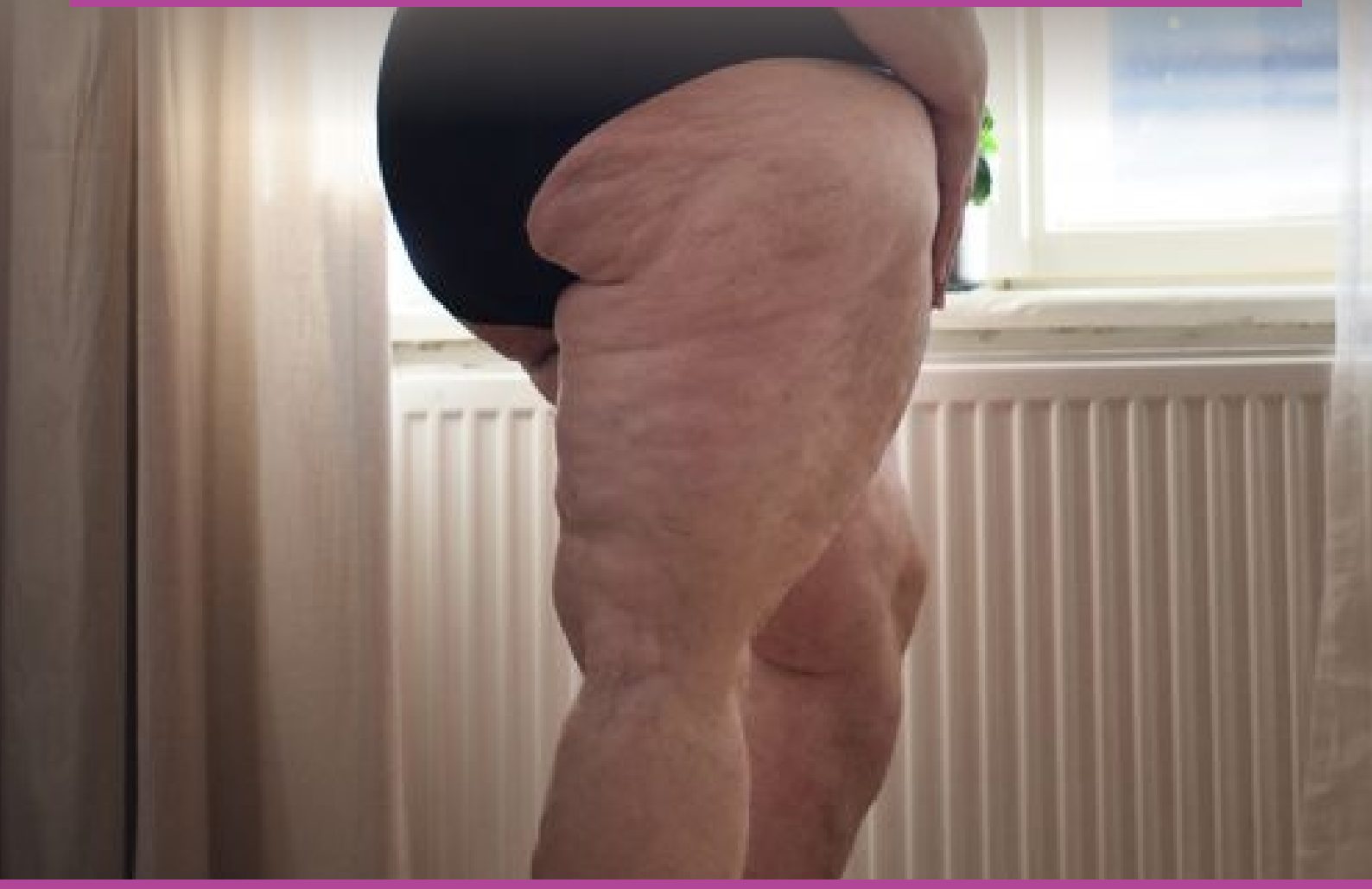
LIPEDEMA

By : Dr. Srinagesh

LIPEDEMA

A Misunderstood & Underdiagnosed **Disease**



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PREFACE

It is for the first time I have attempted to write about lipedema. I was quite helpless and disturbed when I saw my wife complaining of pain in the legs and thighs, a little after marriage, which appeared to be strange for a young lady. Initially thought that she was faking but when she was finding it difficult to keep our baby on her lap due to pain I realized something was not right. As doctors we found it extremely difficult as these symptoms didn't fit into the traditional diagnosis. She was advised painkillers and even antidepressants which didn't appear to be an option. I had the opportunity to visit **Dr. Med. Klaus Uberreitter** in Birkenwirder, Germany where I incidentally came across women similar to my wife's symptoms being treated by him. I had the good fortune to spend a while with him understanding the condition and the way he treated and managed his patients.

Returning back to India in 2010, I imported the equipment with a lot of difficulty. I performed surgery on my wife (with a lot of fear and skepticism). To our surprise, after the surgery she noticed great relief in a very short while and even was able to wear clothes she always desired. Following this was a constant desire to understand the condition and reach out and help individuals suffering from lipedema.

It was not until 2019 that the **World Health Organization (WHO)** recognized lipedema as a separate disease entity and so deferred launching my website www.lipedema.in until then. Since the launch of the website, I have been actively involved in trying to create awareness, educate and enlighten people about this condition which was and is still misunderstood and undertreated as either obesity or lymphedema.

Dr. Pinjala Ramakrishna, a highly knowledgeable and acclaimed senior vascular surgeon learnt about this condition and has been a constant source of encouragement and has helped me in authoring this book.

Dr. V. Sitalakshmi, a gynecologist and dermatologist who is also a lipedema warrior, has been a constant source of encouragement to work and reach out to help women affected by lipedema.

I have tried to keep the book simple and as illustrative as possible primarily to help primary physicians, nurses and health care workers understand the disease and also for people who have lipedema to understand and take steps in the right direction, benefit and have a better quality of life.

INTRODUCTION

Lipedema is a chronic progressive disease which occurs primarily in women and rarely in men. It is characterized by bilaterally symmetrical swelling of the lower extremities caused by deposition of abnormal fat combined with hyperplasia of fat cells. It can be diagnosed using clinical features rather than diagnostic tests. It almost always affects women exclusively and up to 15% of patients have a family history of lipedema [1]. Lipedema occurs primarily in the lower extremities and sometimes accompanied by edema of the upper extremities [2]. Edema of the lower extremities is observed between the pelvic crest and ankle, and occurs symmetrically on both sides [2, 3].

Normal Fat

Lipedema Fat

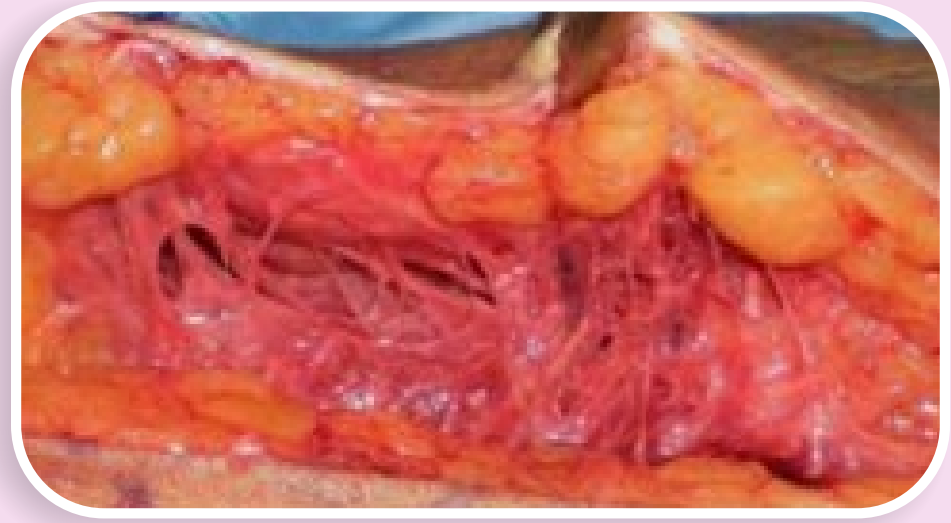


FIGURE 1: APPEARANCE OF NORMAL & LIPEDEMA FAT

WHAT IS LIPEDEMA?

Lipedema is a common adipose and connective tissue disorder that is believed to affect nearly 11% of adult women worldwide[4]. It is bilateral. Symmetrically abnormal fat is distributed in the extremities. There is hypertrophy and hyperplasia of the fat cells. This abnormal fat could be painful and tender on palpation. This fat swellings do not regress even with extreme weight loss measures unlike the truncal fat. Women with lipedema report a rapid growth of the extremities in special and stressful conditions. Hormonal changes seen during puberty, pregnancy or menopause, following major surgery or psychological trauma can precipitate and progress lipedema. Women with classical lipedema can have column like legs, with masses of granular or nodular fat normally confused with cellulite, spider veins and easy bruising.

Though this is a relatively common disease, there are few physicians who are aware of it. Patients are often misdiagnosed as lifestyle-induced obesity, pear shaped or gynoid obesity, and lymphedema. Sometimes they are subjected to medical interventions unknowingly and body fat- shaming too.

Dr. Allen and Dr. Hines[*] at Mayo clinic USA were two physicians who described this condition in 1940. The diagnosis of lipedema was initially established in 1951 and it was based on clinical features. The incidence of lipedema is high and is seen in nearly 1 in 9 adult women. It is essential to generate appropriate awareness, conduct adequate and research and identify better diagnostic and treatment modalities for lipedema. The affected women should get the care and comfort they deserve.

Lipedema is also described as “the painful fat syndrome” or “adiposis dolorosa”. Some think that it is closely related to the more extreme adipose tissue disorder – Dercum's disease.

The exact etiology of lipedema is unknown. Few physicians recognize the constellations of the signs and symptoms to arrive at a proper diagnosis. Women with lipedema are left to suffer due to lack of knowledge along with the misjudgment by family, friends, physicians and strangers.

Women with lipedema are often told to accept their condition as other women in their family also “have big legs”. They are also told that the abnormal growth is the result of their inability to control their dietary habits or due to their sedentary lifestyle. They are usually blamed for noncompliance to the diet and exercise advice. As the disease progresses further, the patients and physicians are disappointed. Women are conscious about their disproportionately growing extremities and increasing weight, coupled by body/ fat- shaming which is common in society nowadays. Women with lipedema suffer from various psychosocial issues like anxiety, depression, and eating disorders which results in isolation.

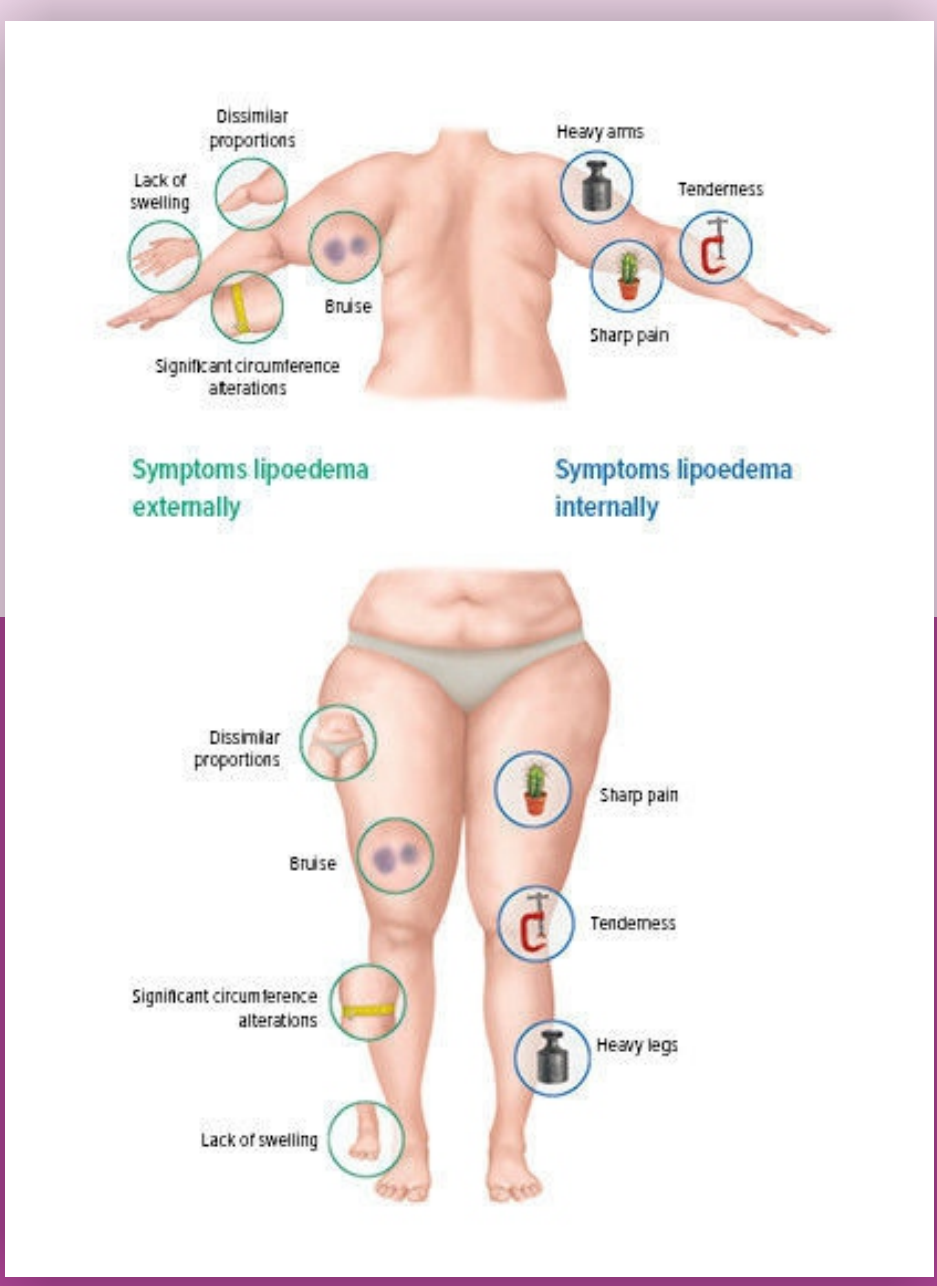


FIGURE 2: CLINICAL FEATURES OF LIPEDEMA.

Dr. Heck – Hamburg, Germany, lipoclinic,
Sulldorfer Kirchenweg 1a, 22587 Hamburg Germany

LIPEDEMA AND ASSOCIATION WITH OBESITY

Some patients with lipedema may also have associated obesity and though one might be a trigger for the other, a mutually exclusive diagnosis for lipedema should be considered. The most common misconception presently is that patients with lipedema suffer from lifestyle or diet induced obesity. The adipocyte hypertrophy and swelling associated with obesity is extremely responsive to diet, exercise, bariatric surgery or caloric restriction. Usually lipedema is extremely resistant to such measures and hence will not regress. In fact, the stress induced by the above methods could actually stimulate or trigger a further growth in lipedema fat.

Exclusive involvement of the extremities is seen in most patients of lipedema. Whereas, in obesity, fat is proportionately distributed in the trunk and extremities. The adiposity associated with lifestyle induced obesity is generally proportionate and spread all over the body. Despite an elevated body mass index, the incidence of diabetes is relatively low in women with lipedema.

IDENTIFYING LIPEDEMA

Suspecting and identifying lipedema can be easy and challenging. Lipedema is typically seen in women and very rarely in men. Lipedema is classically seen to start during puberty, pregnancy or menopause whenever there are periods of hormonal imbalances, especially in women. It can be triggered at any time. Lipedema runs in families in about 60% of the population. Classically, a narrow waist and a progressive increase in the hips and thighs is characteristic of lipedema. As the disease progresses, the fat under the skin becomes granular and nodular and irregular. There is an almost bilaterally symmetrical increase in the buttocks, thighs, legs and in around 30% arms and forearms are affected as well. An abnormal deposit of fat is seen around the knee and elbow joints. This fat is initially painless and can develop occasional to nagging pain as the disease progresses. There is development of spider veins and easy bruising on slight/ trivial injury. Some patients may develop reticular and varicose veins with time along with increase in size of the extremities.

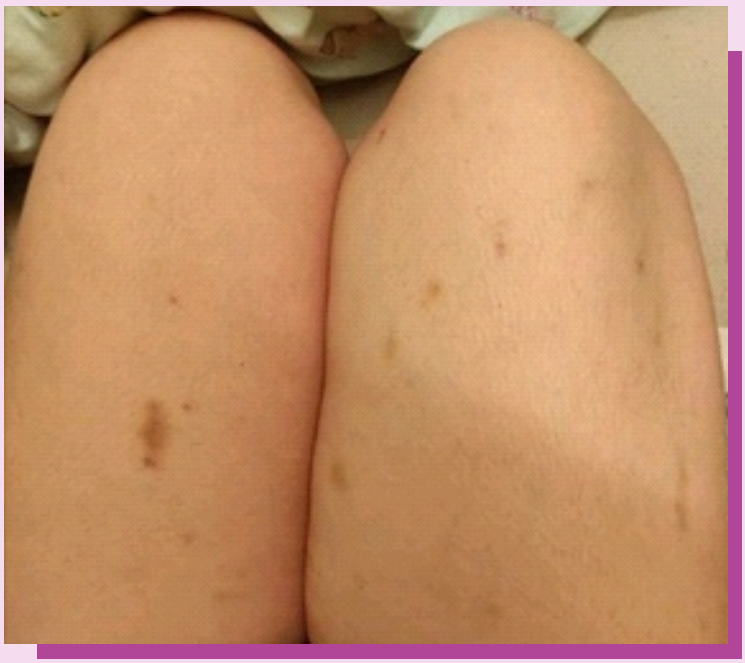
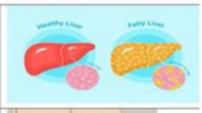
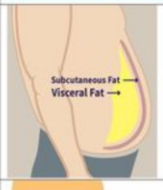
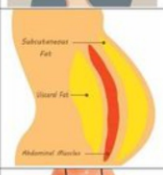


FIGURE 3:
EASY BRUISING ON TRIVIAL TRAUMA

The feet and hands are not affected by the fat deposition until late. The fat is limited to the ankle and wrist giving a cuff like appearance. There is a weakness of the lymphatic system leading to water retention which progresses to lipo-lymphedema and subsequently to frank lymphedema when the feet are also affected. The skin looks paler and the skin temperature is slightly lower than normal. Some of these women have hyper flexible joints similar to Ehlers- Danlos syndrome. Surprisingly, lipedema seems to protect the person from diabetes during the early stages of the disease.

Different types of fat in the body		
Type 1 – Organ fat	Fat is seen in the organs like the bone marrow, liver, and kidneys and is essential for the proper metabolic function of the body	
Type 2 – Visceral fat	Fat or adipose tissue present in the abdominal cavity. This fat is metabolically most sensitive to calorie balance changes. Visceral fat varies in volume depending on the dietary exercise-related calorie excess or calorie deficit situations	
Type 3 – Subcutaneous fat	Fat present between the skin and muscle and is responsible for the retention of body heat and is necessary to cushion the body. Subcutaneous fat is metabolically less sensitive when compared to visceral fat.	
Type 4 - hormone-dependent fat & lipedema	Seen in the subcutaneous region like in type 3. This fat is typically seen in women and the distribution is typically gynoid in nature. The fat is deposited forming the breast, hips, and thighs creating the classical secondary sexual characteristics and giving the feminine shape to the female body. This fat is even less metabolically sensitive than visceral or subcutaneous fat which appears to be closely linked to lipedema.	

As the disease progresses, patients develop knock knees and gait disturbances, leading to frequent injuries to joints, early joint pains and arthritis and early joint replacements. The unexplained pains and joint pains limit the women to be freely mobile and can develop obesity.

FIGURE 4: TYPES OF BODY FAT IN BODY

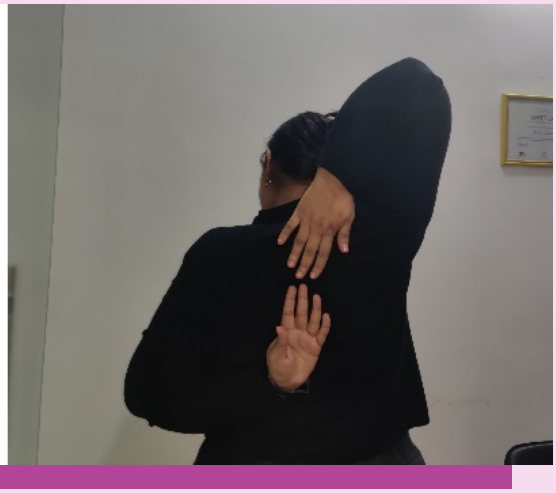
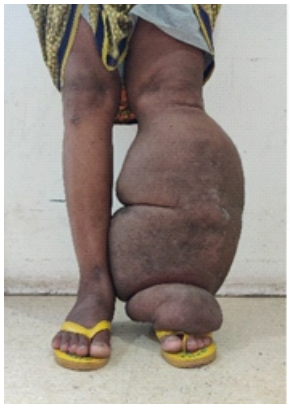


FIGURE 5: HYPERMOBILITY AND HYPERFLEXIBILITY

Lipedema can be associated with obesity, making diagnosis confusing. Lipedema may also be confused with cellulite, Dercum's disease (also known as adipose dolorosa), and lymphedema. Stemmer's sign is a good clinical test to differentiate lipedema from lymphedema [%].



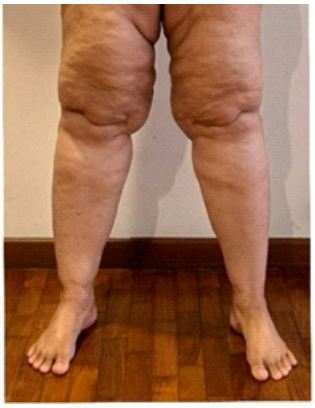
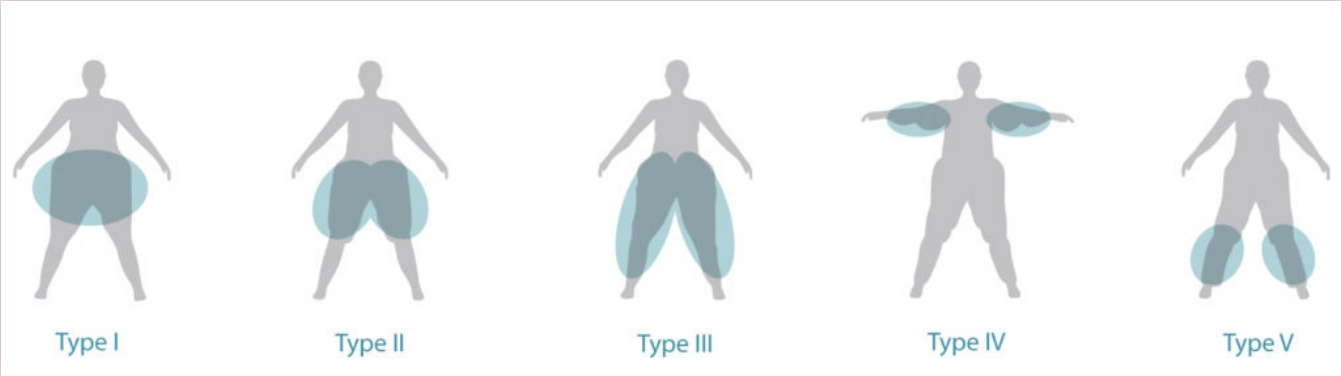


FIGURE 6: DIFFERENCE BETWEEN **LYMPHEDEMA & LIPEDEMA**

Types & Stages of LIPEDEMA

Depending on the deposition of fat,
LIPEDEMA is classified into ***5 types***.



Type 1: often covers the buttocks and pelvis but can extend between navel to hips

Type 2: fat extends from the hips to the knees

Type 3: fat extends from the pelvis down to the ankles. A person in this stage can develop a cuff of fat around the ankles

Type 4: fat spreads from shoulders to elbow and may extend to the wrist and may develop a cuff of fat at the wrist level

Type 5: fat deposits predominantly between the knees to ankles

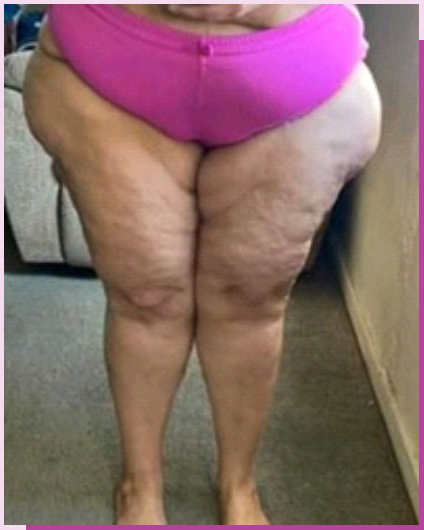


FIGURE 7: A TYPICAL TYPE 2 LIPEDEMA

A combination of type 2 & 3 and type 3 & 5 are more common. A typical type 5 is not very common

Depending on the volume of fat and the lymphatic involvement, ***LIPEDEMA*** is classified into ***4 stages***

Stage 1:

skin appears normal and smooth to touch but small irregular granular or nodular enlarged fat can be felt.

- There may be some tenderness and bruising.

Stage 2:

skin becomes irregular and indentations begin to appear. There could be dimpling.

- Volume of fat increases.

Stage 3:

large skin and fat extensions develop which can appear to protrude out of the skin. These fat protrusions can put pressure on the joints affecting balance and mobility.

- oThere is thickening of tissues due to inflammation.

There is loss of elasticity, leading to a reduced blood and lymph flow out of the fatty tissue causing it to grow further.

Stage 4:

here both lipedema and lymphedema are present.
The lymphatic system is damaged.
Lymphedema develops when lipedema causes the buildup of fat cells to interfere with the lymphatic system.

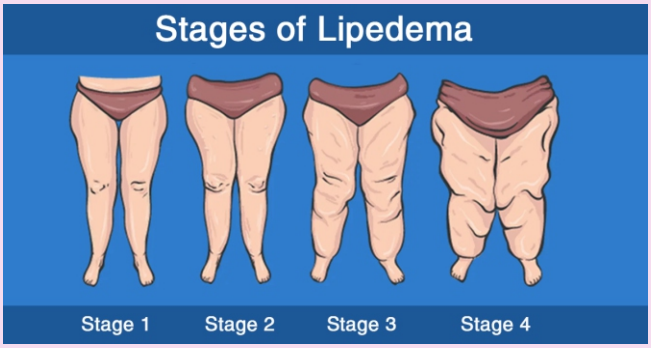


FIGURE 8: STAGES OF LIPEDEMA

https://www.obesityhelp.com/profiles/endocrinologist/karen-herbst/

FIGURE 9: STAGE 2 & 3 LIPEDEMA

FIGURE 10: OBESITY

MANAGING LIPEDEMA

Lipedema reduces the quality of life in a woman significantly, inhibiting their ability to lose weight especially from those areas of the body where lipedema is affected. This puts them at risk for the development of mobility issues, joint deformations and lymphedema. Lipedema increases the risk to develop becoming overweight and obese but can be metabolically friendly until later stages.

There is presently no cure for lipedema. However, lipedema can be effectively managed and the progression can be slowed or delayed by different ways depending on the type, stage and severity of the disease.

Treatments can reduce pain and quality of lipedema fat but only liposuction to date has reduced lipedema fat.

DIET

A low-glycemic diet high in vegetables, certain fruits, healthy proteins (fish or chicken), and whole grains helps to reduce painful swelling and inflammation, and even assists them to maintain their ideal body weight.

EXERCISE

Aerobic exercises such as swimming, walking and cycling are especially recommended because they increase lymphatic drainage and improve blood flow through the affected limbs. High impact exercising (i.e. jogging, step-aerobics) or contact sports are better avoided as they may exacerbate join pain and lead to bruising.

MANUAL LYMPHATIC MASSAGE

This is a gentle form of massage aiming to stimulate the flow of lymph around the body. Free flow of lymph helps reduce the risk of scarring while increasing the blood flow to the area. This helps in pain reduction too.

In 2017 it was found that manual lymphatic drainage massage combined with vibration can effectively treat lipedema.

COMPRESSION THERAPY

Compression therapy by way of crepe bandages and compression garments help in managing lipedema by putting pressure and reducing swelling in the swollen limbs.

LIPOSUCTION

Liposuction is a very effective treatment for lipedema when all conservative measures fail. A hollow instrument called cannula is inserted under the skin with which fatty tissue is broken up and removes it from the body using a high pressure vacuum.

The most effective types of liposuction are:

- Tumescent liposuction: a reasonable volume of wetting solution is injected into the fatty area before removing lipedema fat.
- Water assisted liposuction (WAL): the surgeon uses Klein solution to create a water spray which dislodges the fat for liposuction.

VARICOSE VEINS & LYMPHATIC STASIS

- Some cases of spider veins can cause nagging pain and heaviness which may need intervention for relief of symptoms.
- Extreme tortuosity and increase in size of varicose veins may warrant attention and correction
- Depending on the stage of the disease, lymphatic stasis/ obstruction needs to managed accordingly.

Figure 11: Improvement after 2 sessions of lymph sparing water assisted liposuction

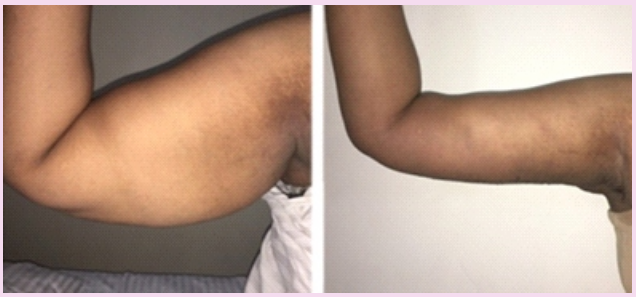


Figure 12: Improvement in the arms with reduction of pain and improvement in function

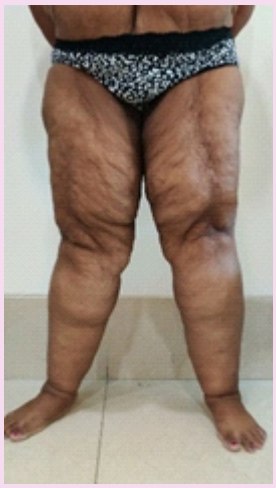


Figure 13: Bariatric surgery helps in weight loss but does not help lipedema

OUTLOOK

There is no known cure for lipedema. The aim to treat lipedema is to improve quality of life so that the person receiving the right treatment can manage their life comfortably.

The consequence of living with lipedema is to experience a poor and devastating quality of life. Lipedema is practically an unknown entity though a common affliction, misdiagnosed, misunderstood and mistreated, which impacts a person's mental health negatively.

The more severe the symptoms, the poorer the quality of life.

One should contact their doctor and discuss their condition, if a person believes she has lipedema. This could be the start of slowing down or halting the progress of the disease.

SUMMARY

- Lipedema is a chronic connective tissue disorder that causes a disproportionate buildup of fat beneath the skin. The condition commonly affects the lower body but can also affect the arms.
- Lipedema almost exclusively affects females and seen rarely in men.
- Common symptoms of lipedema include buildup of fatty tissue in the lower body and arms, pain, easy bruising and spider veins.
- Delay in the treatment of lipedema can lead to reticular veins, varicose veins, lipo-lymphedema and finally to lymphedema.
- Delay in treatment of lipedema can also lead to joint problems like arthritis and early knee replacement.
- Lipedema needs a teamwork consisting of dietician, gym trainer, physiotherapist/ occupational therapist, physician, vascular surgeon, orthopedic surgeon and plastic surgeon and appropriate help should be taken timely.
- Though there is no cure for lipedema presently, there are methods to manage and control the symptoms of lipedema. Joining a lipedema support group is a good way to cope up with emotional aspects associated with this condition.

ABOUT AUTHOR

The author, **Dr. V.K.Srinagesh**, is an experienced plastic surgeon based in Hyderabad, India has good knowledge and is a pioneer in the treatment of lipedema in India. He has been treating lipedema for nearly 10 years. He got his basic training and was mentored by Dr.med. Klaus Ueberreiter from Birkenwerder, Germany who first introduced him into understanding lipedema

Dr. Pinjala Ramakrishna, is a highly experienced and acclaimed vascular surgeon based in Hyderabad, India. He has vast knowledge and is actively involved in education and management of lipedema.

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