

“ It felt like there were two of me. My upper body and lower body didn't match at all. No matter how much I exercised or what I ate, my legs still looked ... puffy. They hurt when something pushed on them, and my doctors couldn't tell me why. Finding out I had lipedema changed everything. I finally stopped blaming myself and started figuring out how to manage my condition. ”



– LINNIE HARDIN
LIPEDEMA PATIENT



Lipedema comes in all shapes and sizes. These are photos of women with varying presentations of the condition. Texture visible in thighs; large legs with small waist; evident swelling; fat above knees and elbows.



Investing in research to define, diagnose, and develop treatments for lipedema.

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What is lipedema?



It's not normal fat.

WHAT IS LIPEDEMA?

Lipedema is a chronic medical condition characterized by a symmetric buildup of adipose tissue (fat) in the legs and arms. A common but under recognized disorder, lipedema may cause pain, swelling, and easy bruising. It may be accompanied by an unusual texture within the fat that can feel like rice, peas, or walnuts beneath the surface of the skin.

The intensity of pain may range from none to severe, and its frequency may be constant, come and go, or only occur when the fat is pushed on. Limited public awareness of lipedema, coupled with few research-backed treatments, can lead to exacerbation of symptoms as well as physical and emotional distress. Common symptoms include fatigue, muscle pain, or easy bruising.



A common feature is hypermobility, where joints stretch farther than normal.

WHO GETS LIPEDEMA?

Lipedema occurs almost exclusively in females, with rare reports of development in men. Although believed to be prevalent, the exact incidence is not known.

WHAT CAUSES LIPEDEMA?

The causes of lipedema are not well understood. It is reported to start or worsen during puberty and other periods of hormonal changes, such as pregnancy and menopause. Research is underway to determine the biological role of hormones, genetics, inflammation, and metabolism in the condition's development.

IS IT OBESITY?

No. Obese fat occurs throughout the body. In lipedema, the fat occurs in the limbs, sparing the hands and feet. People with early-stage lipedema typically do not have diabetes, high cholesterol, or high blood pressure.

IS IT LYMPHEDEMA?

No. The swelling in lymphedema often affects only one side of the body, and includes the hands and feet. Furthermore, lymphedema can be diagnosed with imaging or genetic tests.

Lipedema is not rare, but a proper diagnosis is rarely made.

DIAGNOSIS CHALLENGES

Despite initial medical reports from more than 75 years ago, there are no definitive diagnostic tests for lipedema. It is often misdiagnosed as obesity, lymphedema, Dercum's disease, or chronic venous insufficiency. Underlying lipedema may also be present in patients with these conditions.

Currently the only way to diagnose lipedema is to have a trained physician perform a physical examination with a review of the patient's medical history.

However, few physicians are comfortable diagnosing and treating lipedema because of the lack of diagnostic tests and research-backed treatments.

Therapists may be confident in distinguishing lipedema from lymphedema. Surgeons who perform liposuction are able to remove fat but may not provide broad or long-term care.



Another common feature is fatty pads around the knees.

The Lipedema Foundation is funding research into the development of a conclusive and scalable diagnostic tool as well as into the discovery of better treatment options.

QUALITY OF LIFE

Alongside the physical pain symptoms, lipedema can impact an individual's mental health and quality of life, leading to lack of energy, feelings of hopelessness, low self-esteem, or eating disorders.

Affected individuals are encouraged to speak with their healthcare provider about their mental health. Support groups where patients can share their experiences may also be found through social media. To find these groups, go to Facebook and search lipedema or lipoedema.

WHAT TO DO ABOUT LIPEDEMA

Dealing with lipedema can be a lonely and confusing journey. Typically, individuals with lipedema are encouraged to:

- Improve lymphatic flow
- Reduce inflammation
- Manage pain
- Help your body deal with lipedema
- Get emotional support

Although fat caused by lipedema cannot be lost by just reducing calories and exercising, providers who treat lipedema typically advise daily light to moderate exercise in combination with an anti-inflammatory diet. While surgery such as liposuction can be valuable for some people to manage pain and improve mobility, the decision to undergo surgery must not be taken lightly and should be made in partnership with a qualified medical professional.

HELPFUL RESOURCES

The Lipedema Foundation maintains a resources page – lipedema.org/resources – where you will find everything from self-care videos to ICD Codes. Furthermore, the Foundation has established a registry to help the lipedema community, including clinicians and researchers, learn more about lipedema.

Individuals seeking personalized patient and caregiver support may benefit from visiting the Fat Disorders Resource Society at fatdisorders.org.

FUTURE OF TREATMENT

Each body is different and no single formula works for all. We encourage patients to slowly incorporate different treatments into their routine to see what best works for them. Through the Lipedema Foundation research program, we will continue to study the basic biology, genetics, and epidemiology of the condition with the goal of improving the treatment landscape for everyone with lipedema.