

CLINICIAN'S GUIDE TO LIPEDEMA

Lipedema is a chronic medical condition characterized by a symmetrical buildup of often-painful adipose tissue in the legs, and sometimes the arms and lower trunk (hips, buttocks, and abdomen). It is different from obesity and lymphedema, but may co-occur.

Lipedema is widespread, affecting millions of adolescent and adult women, though prevalence estimates vary.

COMMON PRESENTATION

- Bilateral, symmetrical buildup of fat in the legs, and sometimes arms and lower trunk, that is resistant to nutritional intervention, exercise, elevation, diuretics, and bariatric surgery
- Feet/hands are typically spared, sometimes causing the appearance of an ankle or wrist “cuff”
- Almost exclusively affects women
- Complaints of pain, tenderness, heaviness in affected areas
- Fatigue
- Starts or worsens at times of hormonal changes: puberty, pregnancy, or menopause
- Easy bruising
- Presence of nodular and/or fibrotic texture beneath the skin that can create an uneven, dimpled appearance
- Edema and joint hypermobility may also be present



CLINICAL DIAGNOSIS

Lipedema diagnosis is based on patient history and physical examination to confirm the presence of common signs and symptoms. Currently there are no diagnostic biomarkers or imaging tests.

PATIENT HISTORY

PATIENT REPORTED

- Family history of similar body type
- Difficulty losing fat in affected areas
- Onset/worsening at time of hormonal change
- Pain, tenderness, heaviness in affected areas
- Fatigue
- Brain fog
- Easy tendency to bruise
- Decreased functional ability (including mobility)
- Decreased quality of life
- History of joint issues
- The following treatments have limited to no effect:
 - Elevation
 - Nutritional Interventions
 - Exercise
 - Diuretics
 - Bariatric Surgery

See also the
US Standard of Care



PHYSICAL EXAMINATION

VISUAL INSPECTION

- Bilateral, symmetrical fat accumulation that appears in the legs and may also be present in the arms, buttocks, hips, and/or abdomen
- Disproportion between upper and lower body
- Lobules of fat may present at hips, medial knees, lateral malleoli, or above elbows
- Presence of raised ridge/fold of fat, possibly a “cuff” at wrists and ankles
- Presence of spider veins/varicosities

PALPATION

- Presence of nodular and/or fibrotic texture in affected areas; tissue may feel like rice, peas, or walnuts
- Pain/tenderness in affected areas
- Cutaneous hypothermia may be present

STEMMER SIGN TEST

- Lipedema typically spares the hands/feet and presents with a negative Stemmer sign (a test often used to detect Lymphedema). However, a positive sign does not rule out Lipedema, and likely indicates the presence of concomitant Lymphedema. If both conditions are present, this is termed Lipo-Lymphedema.
- Performing the test: Examiner pinches the dorsal skin proximal to MTP joint of the second toe (or MCP joint of the second finger). If examiner cannot create a fold of pinched skin, this results in a positive sign.

*Some patients and clinicians report Lipedema tissue in other locations

Disclaimer: The Lipedema Foundation is not a medical provider. The information provided in this guide is for informational purposes only, and is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Seek the advice of your physician or other qualified healthcare provider with any questions you may have regarding a medical condition or treatment and before undertaking any new healthcare regimen.

MEDICAL CODING

Frequently used ICD-10 codes include:

- R60.9 - Swelling/edema
- E88.2 - Lipomatosis, not elsewhere classified
- E65 - Adiposity, localized
- Q82.0 - Chronic hereditary edema/lymphedema

EF02.2 - Lipoedema (international spelling) appears in the WHO's ICD-11 revision being utilized by 35 countries. *The United States is still using the ICD-10 revision.*

The American College of Cardiology and American Board of Obesity Medicine include knowledge of Lipedema in advanced training requirements

LIPDEMA IS A DISTINCT DISEASE ENTITY

Multiple studies have found **significant differences** in gene expression, and lipid and metabolite profiles, in tissue, [stem cells], and adipocytes from Lipedema patients compared to non-affected controls" (Ishaq, 2022).

People with Lipedema may appear **metabolically healthy**, including lower tendency toward metabolic dysfunction such as diabetes.

Unlike obesity-related fat, Lipedema-related fat usually **does not respond to nutritional interventions or exercise.**

COMMON TREATMENTS

- Complete Decongestive Therapy (CDT), including Manual lymphatic drainage (MLD)
- Compression garments
- Gentle or aquatic exercise to increase strength, mobility and lymphatic flow
- Ways of eating and supplements to address inflammation
- Specialized Lipedema reduction surgery (includes liposuction)
- Pneumatic compression devices

Research into treatments is still evolving. See lipedema.org/treatments for more.



REFERRALS

Certified Lymphedema Therapists (CLTs)

Specially trained PTs, OTs, or LMTs

Perform MLD, recommend compression garments, tailor exercise programs, and educate about risk reduction and lifestyle modification

Registered Dietitians

Create a tailored eating plan to address pain and inflammation

Surgeons Treating Lipedema

Perform surgery to remove Lipedema tissue. (Always refer to a surgeon that specializes in treating Lipedema)

Individual results may vary and patients should do careful research prior to having surgery

Insurance may cover surgical options for Lipedema. For example, UHC, Cigna, Aetna, and BCBS plans in 35 states have coverage policies for Lipedema surgery

Obesity Medicine Specialists

Make recommendations for managing comorbid obesity (if applicable)

Vascular Specialists

Assess for comorbid vascular disease

Mental Health Professionals

Support patients with impacted mental health and quality of life issues

Support Groups

Facebook groups like Lipedema Sisters USA

Research Opportunities

Patients can visit lipedema.org/legwork to find ongoing clinical studies and lipedema.org/registry to complete the LF Registry Survey



For more resources, visit lipedema.org/clinicians

References

- Kruppa P, Georgiou I, Biermann N, Prantl L, Klein-Weigel P, Ghods M. Lipedema-Pathogenesis, Diagnosis, and Treatment Options. Dtsch Arztebl Int. 2020;117(22-23):396-403. doi:10.3238/arztebl.2020.0396
- Donahue PMC, Crescenzi R, Petersen KJ, et al. Physical Therapy in Women with Early Stage Lipedema: Potential Impact of Multimodal Manual Therapy, Compression, Exercise, and Education Interventions. Lymphat Res Biol. 2022;20(4):382-390. doi:10.1089/lrb.2021.0039
- Crescenzi R, Donahue PMC, Petersen KJ, et al. Upper and Lower Extremity Measurement of Tissue Sodium and Fat Content in Patients with Lipedema. Obesity (Silver Spring). 2020;28(5):907-915. doi:10.1002/oby.22778
- Herbst KL, Kahn LA, Iker E, et al. Standard of care for lipedema in the United States. Phlebology. Published online May 28, 2021:02683555211015887 doi:https://journals.sagepub.com/doi/10.1177/02683555211015887
- Ishaq M, Bandara N, Morgan S, et al. Key signaling networks are dysregulated in patients with the adipose tissue disorder, lipedema. Int J Obes (Lond). 2022;46(3):502-514. doi:10.1038/s41366-021-01002-1