

FDRS 2024

**Supporting Clinicians in the Lipedema Care Journey:
LF Rollout of Lipedema Clinician's Guide & Provider Directory**

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Professional Education Manager, Lipedema Foundation



FAT DISORDERS
RESOURCE SOCIETY

DISCLOSURES

Nothing to Disclose:

The Lipedema Foundation receives no external funding, and sells no products or services.

Disclaimer

This presentation is provided solely to educate consumers on medical issues that may affect their daily lives. Nothing should be considered, or used as a substitute for, medical advice, diagnosis or treatment. Always seek the advice of your qualified health provider with any questions you may have regarding a medical condition.



Poll

Patients

Raise your hand if it took you at least a year to get diagnosed with Lipedema after you first sought medical attention.



Poll

Clinicians

Raise your hand if you are a clinician.



Poll

Clinicians

Keep your hand up if you felt totally confident identifying or diagnosing Lipedema right after you graduated with your healthcare degree.



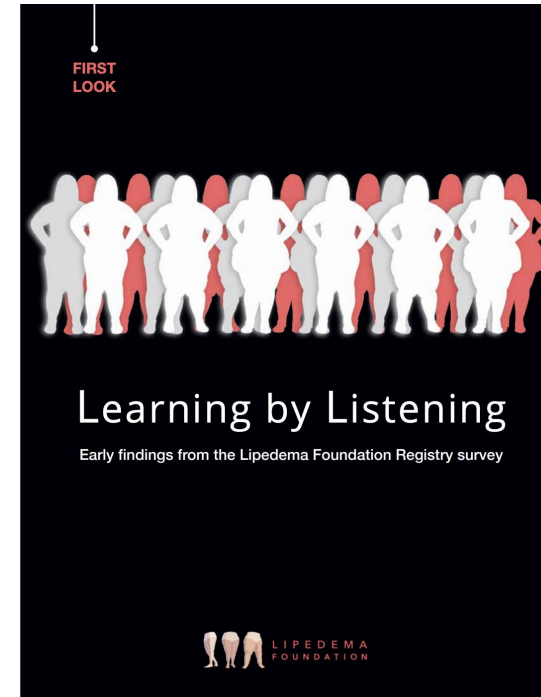
Patient Journey & LF Registry



- On average, women sought medical attention **17 years** after first noticing Lipedema symptoms (Lipedema Foundation, 2022)
- After that first engagement, it typically took another **10 years** to receive a Lipedema diagnosis (Lipedema Foundation, 2022)

57.4%
Report onset of
symptoms around
puberty

48.1
Average Age
of Diagnosis



Download the
First Look Report
for free here:

SCAN ME!



A Gap in the Field



Need for an informational flyer:

- Designed for doctors and other diagnosing providers
- Concise
- Credible
- Visually demonstrative

This sparked the idea for the [Clinician's Guide to Lipedema](#)



Goals of the Clinician's Guide



One-page (front/back) flyer

- **Easy to parse** while providing enough useful information

Legitimize Lipedema as a real condition

Empower clinicians to **feel more confident diagnosing** Lipedema

- Decrease average time to receive appropriate access to care

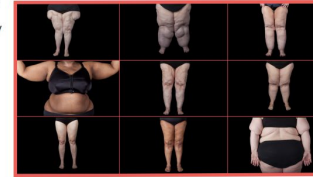
CLINICIAN'S GUIDE TO LIPEDEMA

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	PHYSICAL EXAMINATION
<p>PATIENT REPORTED</p> <ul style="list-style-type: none"> • 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 response: <ul style="list-style-type: none"> • Elevation • Nutritional interventions • Exercise • Diuretics • Bariatric Surgery <p>See also the US Standard of Care</p>	<p>VISUAL INSPECTION</p> <ul style="list-style-type: none"> • 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 modified curvature, possibly a "cuff" at wrists and ankles • Presence of spider veins/varicosities <p>PALPATION</p> <ul style="list-style-type: none"> • 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 <p>STEMMER SIGN TEST</p> <ul style="list-style-type: none"> • Lipedema typically spares the hands/feet and presents with a negative Steemmer 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

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Version 2, March 2024

MEDICAL CODING

Frequently used ICD-10 codes include:

- R03.9 - Swelling/edema
- E88.2 - Lipedematosi, not elsewhere classified
- E65 - Adiposity, localized
- Q82.0 - Chronic hereditary edema/lymphedema

EFD.2.2 - Lipedema (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

LIPEDEMA 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/treating-lipedema](#) 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)

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[Lipedema: A Distinct Disease Entity. *Journal of the American Academy of Dermatology*. Volume 86, Number 5, May 2022. doi: 10.1093/dermatol/ckab388](#)
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Highlights



Common Presentation

- Snapshot of the typical ways Lipedema presents
- Accompanying photos

Clinical Diagnosis

- Walk-through of common patient history reports
- Critical pieces of the physical examination

Medical Coding

- Frequently utilized ICD-10 codes
- Information on the ICD-11 code for Lipedema

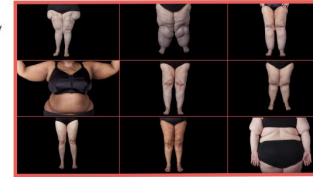
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- Starts or worsens at times of hormonal changes: puberty, pregnancy, or menopause
- Easy bruising
- Presence of nodular and/or fibrotic texture beneath the skin that can create an uneven, dimpled appearance
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3. Ishaq M, et al. Genetic and Metabolic Profiling of Lipedema Patients and Controls. *Obesity (Silver Spring)*. 2022;30(10):1807-1816. doi: 10.1002/oby.23728
4. Hales E, Kahn L, Lee C, et al. Standard of Care for Lipedema in the United States. *Phlebology*. Published online May 26, 2023. doi:10.1002/phle.12557
5. Ishaq M, et al. Genetic and Metabolic Profiling of Lipedema Patients and Controls. *Obesity (Silver Spring)*. 2022;30(10):1807-1816. doi: 10.1002/oby.23728

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Highlights (Cont.)



Common Treatments

- Brief introduction to frequently used treatments in the field
- Link to LF's "Treating Lipedema" webpage for more information

Referrals

- Non-comprehensive list
- Appropriate professionals to which a newly-diagnosed patient could be referred
- CLTs included

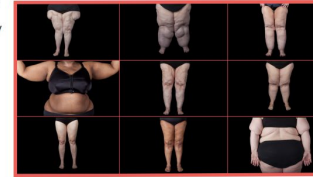
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Clinician's Guide Put into Practice



Patients using the guide as an advocacy tool

- Uploading to their electronic medical records
- Sharing with their doctors via message or in person

Warm welcome from therapists

- Indicated they have searched for a tool to help educate their referring providers not familiar with Lipedema



Download the Guide for Free



lipedema.org/clinicians-guide

Confident in Diagnosing. Now what?



Step #1: Diagnose – Step #2: Refer

One of the suggested referrals in the guide is a therapist who treats Lipedema

- Often a CLT (Certified Lymphedema Therapist)



The role of therapists in Lipedema care



CLTs

- Specially trained to treat lymphatic-system disorders
- Usually receive education on Lipedema
- Often PTs, OTs, or LMTs
- Offer CDT (Complete Decongestive Therapy)
 - MLD
 - Compression recommendations
 - Tailored exercise programs
 - Education for good skin care

Therapists (General)

Therapists can provide

- Manual therapy techniques
- Soft tissue mobilization
- Recommendations for pneumatic compression devices (pumps)

Research has shown that patients with Lipedema benefit from therapy utilizing the approaches listed above

(Donahue et al., 2022; Wright et al., 2022, Atan & Bahar-Özdemir, 2021)

The Problem: Finding a Therapist



- LF is frequently asked for **help to find a professional** who can treat patients with Lipedema
- While other lists of CLTs exist, it can be difficult to identify if a particular CLT **treats patients with Lipedema specifically**
- Some therapists who are not CLTs offer advantageous treatment for patients with Lipedema, but are not on an **easily accessible list**

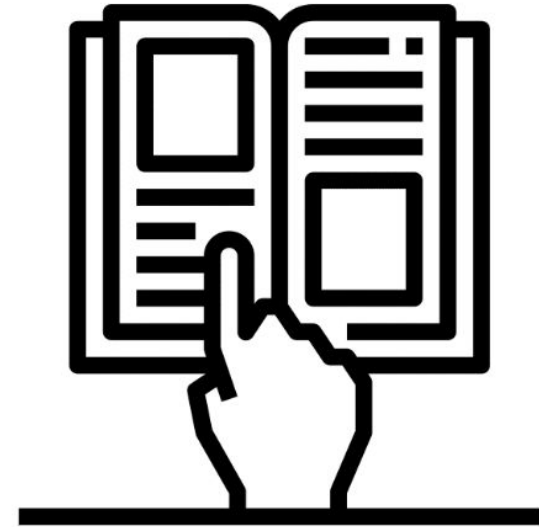
The Solution: LF Provider Directory



Resource designed to help find **therapists** who have identified that they treat Lipedema in their clinical practice

A resource for

- People with Lipedema
- Healthcare providers
- Broader Lipedema community

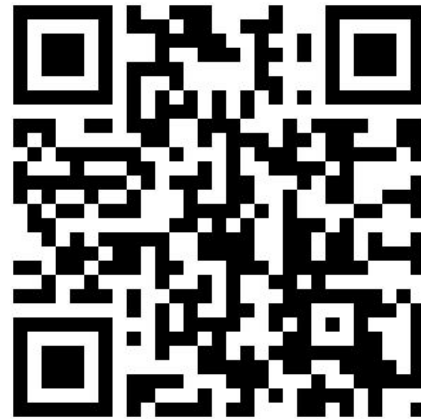


LIVE now

Visit the LF Provider Directory Now!



Access the designated list & start finding therapists
in your area today!



lipedema.org/provider-directory

Patients!

Have a therapist you love who belongs on the list?
Stop by our booth for more info on how to get them in the
LF Provider Directory!



Helpful Patient Education Materials



What is Lipedema?
It's not normal fat.

Patient Self-Advocacy Guide

This guide is intended to help Lipedema patients in the United States no matter where they are in their journey. We believe that every person deserves a timely diagnosis, disease-specific care, and other forms of support. Though there is currently no cure for Lipedema, there are treatments, and we hope this guide will help you navigate your healthcare journey.

Know The Basics

- Lipedema is a **common yet lesser known** chronic medical condition that primarily impacts women and knows no bounds (e.g., age, race)
- Symptoms tend to arise at **times of hormonal change** (e.g., puberty, pregnancy, menopause)
- Lipedema is **characterized by a symmetric buildup of fat** in the legs and arms, whose texture can feel like rice, beans, or walnuts
- Additional symptoms** may include pain, easy bruising, leg heaviness, sensitivity to touch, swelling, cold legs, fatigue, and impaired mobility

Why Self-Advocacy is Essential

- Lipedema is often **misdiagnosed** as obesity or lymphedema, though Lipedema fat is resistant to dietary interventions and exercise
- Misdiagnosis can be related to **presentation with other medical conditions** (e.g., obesity, lymphedema, spider or varicose veins), aka "co-morbidities"
- A timely Lipedema diagnosis can **improve quality of life** for patients
- Many health care professionals **may not be familiar** with Lipedema

	LIPDEMA	VS	OBSESITY
Lipedema and obesity may co-occur			
Areas of excess weight distribution	Extremities sparing hands/feet, can include abdomen*		Entire body
Presence of nodular fat	Yes, especially at later stages		Less common
Tendency to bruise	Frequent		Less likely
Pain associated with fat	Common		Rare
Resistant to dietary interventions and exercise	Common		Less likely
Associated with metabolic or cardiac risks	Less common		More common

*Some patients report fat in other locations

	LIPDEMA	VS	LYMPHEDEMA
Lipedema and lymphedema may co-occur			
Appearance	Bilateral and symmetrical		Often unilateral - may appear bilateral, though is often still asymmetrical
Pitting (indentation remains when pressure applied)	Non-pitting		Involves pitting edema
Presentation	Fat deposits and possible swelling in arms/legs, not hands/feet		Fat deposits and swelling of limb(s) including hands/feet
Skin infections/open wounds	Rare		Common

Source: *Lipedema Pro*

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 health care provider with any questions you may have regarding a medical condition or treatment and before undertaking any new health care regimen. Lipedema Foundation Copyright © 2023

WHAT WOMEN NEED TO KNOW ABOUT LIPDEMA

What it is

Lipedema is a common yet lesser known condition characterized by a symmetric buildup of fat in the legs and arms; the fat texture can feel like rice, beans, or walnuts.

Common Symptoms

- Symptoms often start at times of hormonal change such as puberty, pregnancy, menopause.
- People may experience pain, swelling, easy bruising, leg heaviness, sensitivity to touch, cold legs, fatigue, and impaired mobility.
- Compromised mental health and quality of life can lead to low energy, eating disorders, and feelings of hopelessness and low self-esteem.

Prevalence

Lipedema primarily impacts women and knows no boundaries, crossing many demographics like age, race, ethnicity, and education. Though comprehensive epidemiology data is lacking, Lipedema has been said to impact 5-12% of women.

Diagnosis Challenges

- Right now, there isn't a laboratory or imaging test for Lipedema. Qualified doctors can diagnose in their clinics.
- Since Lipedema affects many parts of the body, diagnosis and management can include many types of healthcare professionals (see lipedema.org/medical).
- Certified Lymphedema Therapists (CLTs) are most familiar with Lipedema; they likely cannot diagnose but may know a doctor who can.

Common Misdiagnoses

- Lipedema is often misdiagnosed as obesity, though it is resistant to dietary interventions and exercise and involves disproportionate fat accumulation in the limbs, sparing the hands and feet.
- Lipedema is also often misdiagnosed as lymphedema, though lymphedema usually only affects one side of the body and includes the hands and feet.
- Misdiagnosis of Lipedema can also be related to the presence of other conditions such as spider or varicose veins.

Treatment

- Current guidelines recommend conservative therapies such as specialized compression garments and manual lymphatic drainage (MLD).
- If you are considering surgery, know that every surgeon has a different philosophy and approach. Do your research as pre- and post-operative protocols can vary and outcomes data for surgeons are hard to come by.

For the latest information, resources, and research visit lipedema.org

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lipedema.org/brochure

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BRAND NEW “For Clinicians”

section of our website

- Diagnosing Lipedema
- Treating Lipedema
- Clinician’s Guide
- ICD Codes
- Videos & CME
- & much more!



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April 19-21



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