



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

	L I P E D E M A	V S	O B E S I T Y
	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

	L I P E D E M A	V S	L Y M P H E D E M A
	Lipedema and lymphedema may co-occur		
Appearance	Bilateral and symmetrical		Often unilateral + may appear bilateral, although 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: [Lympha Press](#)

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.



How To Find A Care Provider

There is no definitive laboratory or imaging test for Lipedema, and since Lipedema affects many parts of the body, diagnosis and management can include many professions. To learn more about the types of healthcare providers you might connect with, visit lipedema.org/findspecialists; meanwhile consider these starting points.



Ask in **Lipedema social media groups** for recommendations for providers who diagnose and treat Lipedema

Follow up with your own research on recommendations and be sure to check if providers are in your health insurance network if you are not planning to pay out-of-pocket. Keep in mind that while you may receive recommendations for plastic surgeons, conservative therapies such as manual lymphatic drainage (MLD) and specialized compression garments are among recommended treatments.

“Work backwards” by finding a **Certified Lymphedema Therapist (CLT)** in your area and ask if they know local doctors who can diagnose Lipedema

A growing group of specialized physical, occupational, and massage therapists are familiar with Lipedema and some are trained to treat it. CLTs are most familiar with Lipedema and while they most likely cannot diagnose, they may know a doctor who can. You may consider starting your search for local providers using these provider directories.

- [Lighthouse Lymphedema Network in GA and US/Outside of GA](#)
- [Lymphology Association of North America](#)
- [Klose Training Lymphedema Certification](#)
- [Academy of Lymphatic Studies](#)
- [National Lymphedema Network](#)
- [Lymphedema Association of Ontario](#)
- [Dr. Vodder School International](#)



Seek out a **vascular doctor**

A vascular specialist can determine if comorbid vascular diseases, such as venous insufficiency, justify treatments like venous ablation – or if conservative measures suffice. As venous procedures have not been found to effectively treat Lipedema symptoms, be sure to ask your clinician for clarification if these procedures are being recommended, as well as information on non-invasive, conservative treatments.

Note: Many providers, unless in a closed HMO, will not confirm anticipated appointment costs prior to billing. If you would like to know if a provider is in-network, ask for their National Provider Identifier (NPI) number, which is a unique number issued to U.S. healthcare providers and organizations. You can then call your health insurance carrier and give them this number to ask about coverage.





Engaging In Care

As a patient, you deserve to be listened to with respect and without bias, stereotypes, or preconceptions. Seek another opinion if your provider is not open to discussion. And if you feel that your mental health is impacted by your condition, tell your primary care physician how you are feeling so you can obtain resources and referrals.

What To Ask

Ideally before you set up an in-person visit, ask these preliminary questions and note the following considerations:

“Do you know what Lipedema is? Have you treated others with Lipedema before?”

Watch for confusion with conditions with similar names; for example “lymphedema” (swelling in an arm or leg caused by a lymphatic system blockage, not fat) and “hyperlipidemia/lipidemia” (conditions related to cholesterol/lipids circulating in the blood, not fat). Beware of doctors who say “Lipedema is just obesity,” tell you to lose weight, or dismiss Lipedema as a social media fad/internet disease.

“What treatments have you recommended people with Lipedema try, other than surgery?”

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, and pre- and post-operative protocols can vary. Be sure to do your research and know that data on outcomes for individual surgeons are hard to come by.

“Do you work closely with any other clinicians when treating your Lipedema patients?”

Effectively treating patients requires a multi-disciplinary approach due to the Lipedema co-morbidities. Most doctors informed about Lipedema understand that it will be a team effort to effectively treat Lipedema patients.

Appointment Preparation & Follow Up



These **resources** can be helpful in conversations with physicians and might even serve as the spark for your provider to learn more about Lipedema after your appointment.

- Lipedema Foundation [“What is Lipedema” Brochures](#) (request as many as you need at no cost)
- [Executive summary](#) of the findings of the Lipedema Foundation Registry survey
- The published [Standard of Care for Lipedema in the United States](#)



Healthcare appointments are often 15 minutes or less. Prepare a **45-second elevator speech** about your experience with Lipedema, including highlights such as onset of symptoms, treatments tried, providers you have or are currently working with, and date of diagnosis if applicable. You could choose to bring this to your appointment and request it be added to your electronic medical record.



Because Lipedema is a lesser-known disease, you may encounter providers who are less knowledgeable or outright dismissive of your lived experience or diagnosis. If you encounter **a provider who does not provide the support** you are looking for, allow yourself to feel frustrated but don’t stop there. Continue to seek out a new provider who can offer the type of support and bedside manner for which you are searching.

