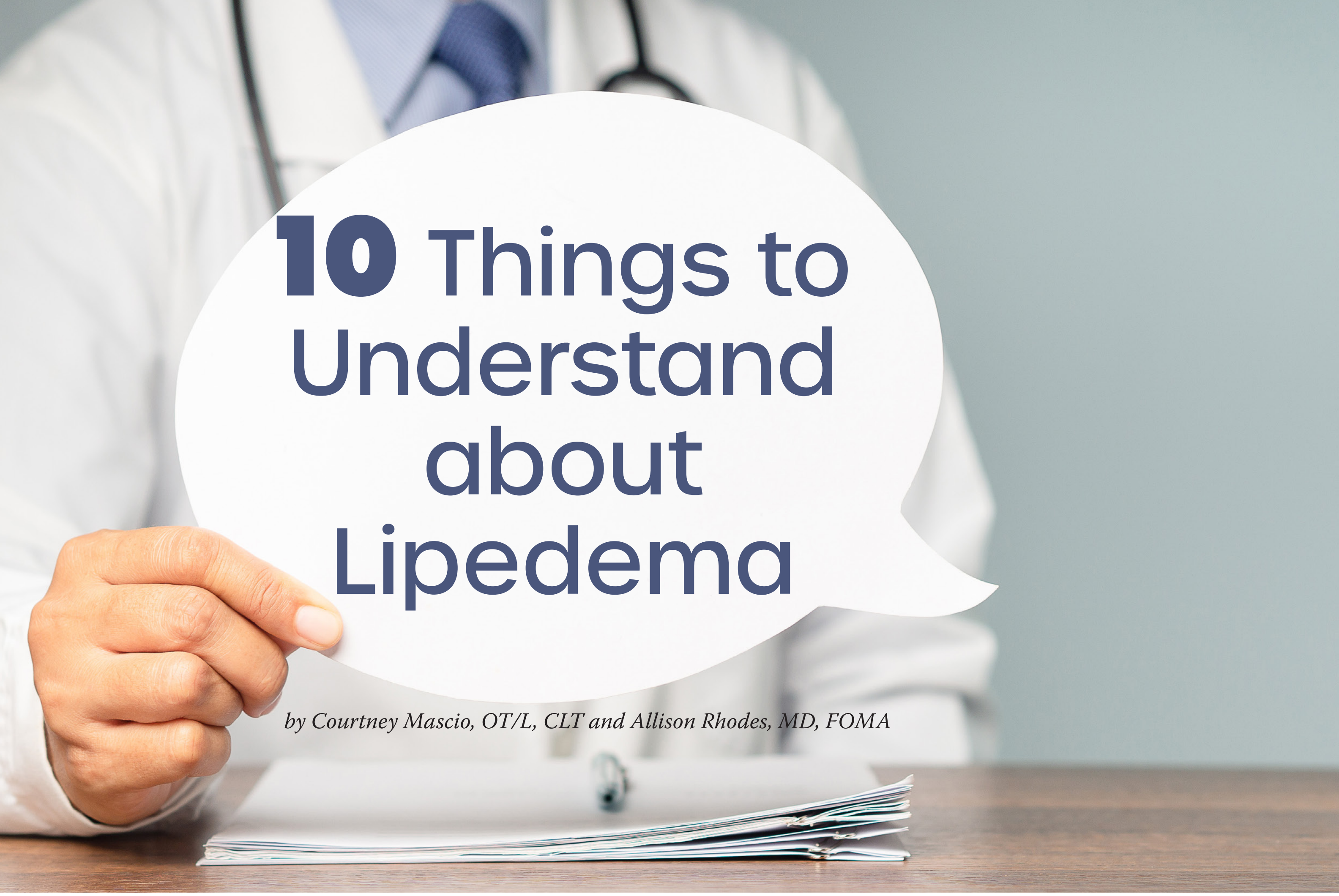

10 Things to Understand about Lipedema

by Courtney Mascio, OT/L, CLT and Allison Rhodes, MD, FOMA

Lipedema is a misunderstood and often overlooked condition that affects millions of women, yet many have never heard of it. It causes a painful buildup of fat in the legs, arms and other areas, and doesn't respond to typical weight loss methods like dieting or exercise.

Lipedema is often confused with obesity, and while the two conditions can exist together, they are not the same. Because it's not widely known even by healthcare providers, it's often misdiagnosed or dismissed, leaving many women confused, frustrated and without answers for years. If you've ever felt like your body isn't responding the way it "should," this might help you understand what might be going on and what to do next.

1. Lipedema is under-recognized but not rare

First described in the 1940s by Allen & Hines at the Mayo Clinic, Lipedema (pronounced lip-uh-DEE-muh) is a painful* fat disorder that occurs almost exclusively in females and makes losing weight in the legs and sometimes arms, buttocks and hips difficult. (The abdomen can also be affected but this is less common.) Lipedema can cause the torso to appear disproportionately smaller than the limbs. Many women report sentiments like: "I can lose weight in my face, chest or upper abdomen, but my legs and arms never change." Though it is estimated to affect millions of women, it is often under-recognized and confused with obesity or lymphedema (a condition that causes chronic swelling due to problems with the lymphatic system.) Lipedema is diagnosed clinically, meaning there are no blood or imaging tests. Due to a lack of provider education and awareness, it takes an average of a decade after entering the medical system for a woman to receive a proper diagnosis.

*Note on pain: Some clinicians consider reported pain essential for diagnosis and may not diagnose Lipedema without it. Pain is subjective and may become harder to recognize over time. Patients should describe sensations in affected areas compared to unaffected ones—like discomfort, tenderness or heaviness—to help their provider understand symptoms and impact.

2. Lipedema is not caused by eating too much or a lack of exercise

Lipedema-related fat is "stubborn" and doesn't respond like typical fat tissue to caloric reduction or increased exercise. Many women report weight loss in some areas but little or none in the legs or arms. Obesity is a common comorbidity, and difficulty losing fat in certain areas may indicate Lipedema. Like obesity, Lipedema is not caused by laziness or a lack of willpower. It is a real chronic condition that deserves individualized care and a comprehensive treatment approach.

3. Lipedema often starts or worsens during hormonal changes

Many women first notice symptoms at puberty, reporting things like: "Even though I ate the same foods as my friends, my legs got much bigger and felt heavy and painful." Others notice onset or worsening during pregnancy or menopause.

4. Lipedema isn't just fat in the limbs

Lipedema tissue can come with symptoms like painful lumps or nodules, skin thickening (fibrosis), pain when touched, bruising without trauma, heaviness in the limbs, brain fog or fatigue. These symptoms can impact mobility and quality of life.

5. Lipedema looks different for everyone

Lipedema presents differently based on the type and stage of the condition. Some women have minimal fat buildup, while others experience severe fibrosis, pain, limited mobility or fatigue. A Lipedema specialist can help determine if you have the condition and start treatment.

6. There are no blood or imaging tests to confirm Lipedema

While research on biomarkers is ongoing, Lipedema is currently diagnosed clinically. A provider will take a detailed history and perform a physical exam.

7. Lipedema can seriously affect mental health

Many women with Lipedema have been told their pain is imagined or that they're not trying hard enough to lose weight. Combined with the burden of chronic pain, this can lead to depression, anxiety, isolation and body image struggles. Mental health care is a vital part of managing Lipedema. Support from mental health professionals and personal networks can make a meaningful difference.

8. Managing Lipedema may require multiple providers

Because Lipedema affects many systems, care may involve:

- Primary care provider: rules out other conditions and refers to specialists
- Obesity medicine specialist: helps if obesity is also present
- Vascular medicine specialist: evaluates for venous disease if symptoms overlap
- Rehabilitation professionals: includes occupational, physical or massage therapists trained in Lipedema
- Mental health professional: helps address emotional and mental health challenges

9. There are treatment options

Though there's no cure, treatments can reduce pain, inflammation and improve mobility and quality of life. Options include compression garments, manual lymphatic drainage (MLD), pumps, anti-inflammatory nutrition, aquatic exercise, fibrosis treatment tools, medications, supplements and mental health support. Surgery to remove Lipedema fat is also an option for some.

10. You are your best advocate

Many providers aren't familiar with Lipedema, and misdiagnosis is common. Advocating for yourself is key to receiving proper care. Try these strategies:

- Track symptoms: log pain, swelling, fatigue or mobility issues
- Take photos: show changes over time
- Bring support: a trusted person can help at appointments
- Write down questions: ensure you don't forget concerns
- Educate your provider
- Find a support group
- Download the Lipedema Foundation's Patient Self-Advocacy Guide at **Lipedema.org/guide** for more tools.

Lipedema may be under-recognized, but awareness is growing. Understanding the signs can lead to better care, a timely diagnosis, treatment and support. To learn more, watch our OAC Fresh Perspective episode on Lipedema at **https://www.youtube.com/watch?v=Q6m5uuQ3OSA**

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The Obesity Action Coalition (OAC) is a National non-profit organization dedicated to giving a voice to individuals affected by obesity and helping them along their journey toward better health. Our core focuses are to elevate the conversation of weight and its impact on health, improve access to obesity care, provide science-based education on obesity and its treatments, and fight to eliminate weight bias and discrimination.


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