

The Patient's Bill of Rights

A resource for advocating for a diagnosis and effective treatment.

Every person with Lipedema deserves to have timely diagnosis and treatment options. This Lipedema Patient's "Bill of Rights"* is designed to help patients navigate the process to get a proper diagnosis and find effective care, and overcome obstacles due to systemic and cultural bias.

Lipedema is not rare, but a *proper diagnosis is rarely made*, leaving many people cut off from treatment options.

The Lipedema Foundation believes that every person deserves a timely diagnosis, disease-specific care, and other forms of support. To help achieve this, we have worked with patients and healthcare providers to develop and share strategies to help you navigate the frustrating process of seeking care.

Not everyone will be able to pursue all of these strategies. Your specific symptoms, insurance coverage, and even location may make a difference. Also, some obstacles are systemic. In an ideal world, all healthcare providers would provide compassionate, appropriate care to those who need it. But these ideas might help increase your chances of getting a diagnosis and effective care.

We are interested to hear what has been successful for you. Share your thoughts at info@lipedema.org.



Scan the code for links and more information.

Here's our list of 10 Lipedema patient rights:



A timely diagnosis

A timely Lipedema diagnosis can increase and improve your treatment options. If you suspect you have Lipedema, ask your healthcare provider to consider that possibility. Many providers may not be familiar with Lipedema. Lymphedema therapists have been the most reliable identifiers of Lipedema, and some vascular doctors have expertise in diagnosing the condition. Seek another opinion if your provider is not open to discussion.

- Share the [U.S. Standard of Care for Lipedema](#) and "[What is Lipedema?](#)" brochure with your providers.



A healthcare team

Lipedema can affect many parts of the body, so care management may include working with a variety of health professionals. **Consider having a healthcare team in place to help manage your symptoms.** The team may include primary care doctors, nutritionists, therapists, mental health professionals, and others. But many specialists are unfamiliar with Lipedema, so make sure they have some knowledge or are willing to learn about the condition.

- For a general overview, share the "[What is Lipedema?](#)" brochure with your care team and for an in-depth look at living with the condition from the patient perspective, share the [LF First Look Report](#).



Comprehensive symptom management

Though there is currently no silver-bullet cure for Lipedema, **symptom management strategies are available to help patients.** The best way to access these strategies is to be informed about them. Your care may involve a combination of treatments, such as physical activity or compression garments. In certain cases, liposuction or reductive surgery may be options for some people, but are not always available or recommended.

- Explore [conservative treatments](#).



Disease-specific care at any weight

Because Lipedema can appear alongside obesity, providers may not always distinguish the two. But Lipedema is not the same as obesity. **Some people with Lipedema may need special accommodations due to their size.** Don't be afraid to ask for a large-sized exam gown or blood pressure cuff, or to be weighed in a private area.

- Learn about the differences between [Lipedema and obesity](#).



Realistic treatment options and expectations

Be wary of bad actors who promise a cure or quick fix to Lipedema. Ask your provider about realistic treatment options and symptom management. Any healthcare provider should give you clear, transparent answers about their own patients' outcomes—both good and bad.

- If you have questions about a physician's reputation or treatment plan, see if there are any complaints filed through [State Medical Boards](#).



Know what the cost of treatments will be upfront

Your provider should **discuss the costs of care** when developing your treatment plan. Make sure you obtain affordable treatment options. Not all non-surgical treatments are covered by health insurance – find out what out-of-pocket costs may be before beginning any treatment. Be upfront with your provider if the recommended treatment(s) present a financial hardship. Work with their office staff to find more affordable alternatives.

- Contact your health insurance provider for assistance. If you live in the U.S. and don't have health insurance, visit [Medicaid.gov](#) and [Healthcare.gov](#) for information and resources.



Mental health resources

Although depression and anxiety occur at higher rates among people with Lipedema, not all providers may initiate conversations about patient mental health. If you are experiencing symptoms, tell your provider how you are feeling so that you can obtain a mental health screening and get resources and referrals that can help.

- Check out these [resources](#) for more urgent care.



Respectful, stereotype-free care

In certain situations, you may feel as if you are not being treated with respect. For example, studies show that women's pain is more likely to be taken less seriously than men. If you are a woman, be aware of these types of gender bias. **You deserve to be listened to with respect and without bias, stereotypes, or preconceptions.** If a healthcare professional is dismissive of your experience, seek another provider.

- Seek out Lipedema support groups on Facebook for help with finding local providers. Also, check out the Fat Disorders Resource Society (FDRS) [website](#) as well as its [YouTube](#) channel for additional resources.



Informed dialogue

Care for Lipedema should be individualized, and that requires dialogue between you and your provider. Expect providers to be responsive to open dialogue and if not, seek a different provider if efforts at communication are ignored or dismissed.

- Watch this [video](#) from Dr. John Bartholomew of the Cleveland Clinic on overcoming fat bias by doctors.



Continuing to learn about Lipedema

Research on Lipedema is constantly evolving and growing. Stay informed as recommended treatments and protocols evolve by consulting the Lipedema Foundation's [website](#), which has tools that can help you find research studies and recruitment opportunities for clinical trials.

- Check out the [Legato Library](#) for peer-reviewed articles, and advance research by participating in the Lipedema Foundation [Registry](#) or using the [LEGWORK](#) tool to search for clinical trial opportunities.

**Please note that the term "Patient's Bill of Rights" is sometimes used by medical providers (e.g., hospitals, doctors' offices) to disclose rights, expectations and entitlements belonging to patients. The Lipedema Foundation is not a medical provider, and we can't guarantee that you will receive these rights from your healthcare providers. Our hope in sharing this document is to present a framework and to share strategies and resources that might help you in pursuing a diagnosis and effective care from licensed medical professionals.*



Scan the code for links and more information.