

FDRS 2023 April 14-16



FAT DISORDERS
RESOURCE SOCIETY

Advancing a Lipedema Patients' Bill of Rights

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Lipedema Foundation

lipedema.org/fdrs



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.



The Lipedema Foundation Team



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Show of hands: Who here has...

Felt dismissed or disrespected by a medical provider when seeking a diagnosis or treatment?

Been told to "just eat a little less / exercise more"?

Felt they received substandard medical care because of their size or medical condition?

Felt discriminated against in a healthcare setting?

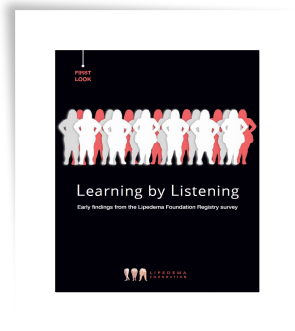
Felt like you knew more about Lipedema than your medical provider?



Why a patient's bill of rights?

39.6
Average Age
Seeking Help

48.1
Average Age
of Diagnosis



Source:
Lipedema Foundation
Registry

- Average time to diagnosis > 8 years
- Patients dismissed by providers
- Hospitals have a “Patient’s Bill of Rights”
- This is a little different!
 - Lipedema Foundation is not a medical provider

Patients should be entitled to respect and effective care



Lipedema Patients' Bill of Rights



- 10 aspirations for better healthcare for people with Lipedema
- Resources for patients to learn and self-advocate



lipedema.org/rights



How was this created?

- Interviewed Lipedema patients, physicians, and therapists about the experience seeking diagnosis and effective care
- Drafted “rights” - expectations we think patients are entitled to
- Reviewed it with additional patients to understand what resonated, and what didn't
- Soft launched in late 2022

We want feedback to make it more useful



Limitations: This isn't enough...



- Systemic problems in healthcare
- Bias (including weight bias) is real
- Racial and gender bias
- Access care depends too much on who & where you are, and your resources



Jaime's story - more on our blog



REGISTRY Research Understanding Resources Events Fu

June 11, 2021

Seasons Change

By Jaime Soderberg

I can vividly recall my nine-year-old self walking the aisles of a local department store with my mother in a quest for a new summer wardrobe. Out of the corner of my eye, I spotted it: the perfect striped summer dress. Sprinting to the dressing room, mom helped me get the dress over my head. Hurriedly, I poked my arms through the holes when suddenly devastation struck. I was stuck, really stuck! Mom pulled, tugged, twisted, and turned as she tried to force those capped sleeves over my chubby upper arms. With a final double fisted yank, off flew the dress. Just like that, my summer dreams lay balled up on a dressing room floor.



This incident became a pivotal moment in a lifelong progression of dressing room nightmares. My weight gain continued. My arms and thighs kept growing despite my active lifestyle. Early on, I came to the realization that something about me was just different. Didn't all middle schoolers go to a diet center and

lipedema.org/jaime



Right to a Timely Diagnosis



- **A timely diagnosis can increase and improve treatment options**
- If you suspect you have Lipedema, ask your healthcare provider to consider it
- Many providers not familiar with Lipedema
- Seek another opinion if your provider is not open to discussion



Right to a Timely Diagnosis: Resources

Share

Search

- Lipedema Foundation “What is Lipedema” brochure
- U.S. Standard of Care for Lipedema
- Look for local therapists from organizations such as LANA (Lymphology Association of North America)
 - <https://www.clt-lana.org/therapists>
- Ask other patients in online discussion groups (e.g., Lipedema Sisters on Facebook)



Disease-specific care at any weight

- Providers may not always distinguish Lipedema from obesity. But they are not the same.
- **Some people with Lipedema may need special accommodations for 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.



Disease-specific care: Resources

Learn

- Dr. Jerry Bartholomew, Cleveland Clinic, FDRS videos
- 2016, “Overcoming Fat Bias from your Doctors”
 - <https://youtu.be/rWSaQjw9Fv4>
- 2017, “Help! I Can’t Find a Local Doctor to Help Me!”
 - <https://youtu.be/MYrmh3sJuCY>

Share

- LF Resources on differentiating Lipedema and Obesity:
 - <https://www.lipedema.org/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



Realistic treatment options and expectations: Resources

Learn

- LF's page on treatments:
 - <https://www.lipedema.org/treating-lipedema>
- FDRS' self-care playlist:
 - <https://youtube.com/playlist?list=PL1UXN1MUyFzXTK3PesPG3cT413XYRvMSz>

Search

- If you have questions about a physician's reputation or treatment plan, see if there are any complaints filed through State Medical Boards.
 - <https://www.fsmb.org/contact-a-state-medical-board/>



What we've heard so far

"Thank you for this great resource."

"I'm not sure Lipedema patients can 'go deeper'. We work full-time to manage our treatment and care."

"I wish we had a caseworker assigned to every patient who needs complex care."

"It is important to acknowledge additional barriers because of a patient's income, geography, race...[and] gender."

"This is incredible, and a great source of information."

"I would like to see this ... [adopted by] the WHO and approved for all countries as a platform for worldwide acceptance of Lipedema."

"The [resource] links are amazingly informative."



Next steps

- What resonates? What doesn't? What's missing?
- What other resources have been helpful for you?
- What ideas do you have for how we might use this to:
 - Help people with Lipedema?
 - Turn more healthcare professionals into advocates for people with Lipedema?
- Share with others who might benefit



We want input from providers, too

- How does this “land” for healthcare providers?
- How can patients better prepare themselves for a conversation with you? Your colleagues?
- Convince others to take Lipedema patients seriously, to learn how to diagnose and treat them



Acknowledgements

- Patients who contributed and gave feedback
- Physicians and therapists who contributed their time and perspective
- Dana Carluccio & team at Rose Li Associates





- This Bill of Rights won't solve everything
- Others have succeeded in getting a diagnosis and care
- Know there are people out there who care



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Come by our booth

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Crowne Plaza Atlanta Perimeter at Ravinia
Atlanta, GA

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