

MASSAGE THERAPIST'S GUIDE TO LIPEDEMA

By Kathleen Lisson, CLT

Author, "Lipedema Treatment Guide"





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I can't seem to lose weight on my legs and bum, no matter what I do.
I can't find clothes to wear - I am different sizes on the top and bottom.

My family tells me I have my grandmother's legs.

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LIPEDEMA is a chronic, progressive and painful adipose tissue disorder thought to affect around ten percent of the female population in America. Lipedema, also called lipoedema, was first described by Doctors Allen and Hines of the Mayo Clinic in the 1940's. Almost 80 years later, the condition is often mistaken for 'obesity' based on BMI.



THINGS YOU NEED TO KNOW ABOUT LIPEDEMA

What is it?

Lipedema is a chronic, progressive and painful fa tissue disorder. You might also see it written as lipoedema or lipodem as well

- When was it discovered?

 It was first described by Doctors Allen and Hines of the Mayo Clinic in 1940.
- When is typical onset?

 46% of women with lipedema symptoms said their symptoms started in puberty (Fetzer & Fetzer,
- Where on the body is it noticed?

 Typically, it is seen on the butt, thighs and calves at puberty. It can sometimes affect the arms.
- Is there a cure?

 There is no pill or operation that can instantly cure lipedema. It is a condition that needs to managed to reduce severity of symptoms.
- What are common symptoms?

 Pain with pressure, bruise easily, heaviness and/or weakness in legs, fatigue, smooth skin, but "bean bag' like below skin.
- 7 Is it hereditary?

 Many people with lipedema have noticed a familial link, but more research is needed to determine a genetic link.
- Are there any other symptoms?

 Hypermobility, frequently cold body temperature, and some report the skin on their legs is a different temperature from the rest of their body.
- Is weight loss an effective treatment?

 No. Research has found that there is "little support for the notion that diets lead to lasting weight loss or health benefits" (Mann et al., 2007)
- ls it caused by my eating habits?

 No! Having lipedema is not your fault!

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HERE ARE 5 WAYS TO IMPROVE YOUR WELLBEING

Treatment Goals for Lipsedema



1.) REDUCE PAIN AND INFLAMMATION

Gentle massage act to calm the sympathetic nervous system which reduces nerve pain and sensitivity. Manual lymphatic drainage improves the flow of lymph throughout your body which reduces pain and swelling.

2.) ENHANCE SELF-CARE PRACTICES

Improving the amount and quality of your sleep, reduce the amount of stress in your life, reach out for help and support when needed, increase activities you enjoy, laugh, and take time to attend to your emotions.





3.) MAKE MOBILITY AND PHYSICAL ACTIVITY PLEASANT

Stop thinking "No pain, no gain." Let go of using physical activity as a way to change the shape of your body. Start focusing on moving in ways that you enjoy. We weren't meant to use movement as a way to punish ourselves.

4.) IMPROVE PSYCHOSOCIAL WELLBEING

Seek out a therapist to support you with the effects of weight discrimination, improve your ability to experience distress and emotions without acting on them, increase your social connectedness virtually and in real life, and try meditation.



5.) INTUITIVE EATING



Recognize that dieting doesn't work long-term or improve your health and that your size doesn't determine your health. Make peace with food and respect your body's intuition. Practice eating based on internal cues, not external cues. If this sounds extremely challenging, find and work with a dietitian, therapist, and/or coach on learning how to do this.

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How Massage Therapists Can Help

- ✓ If there is pain and tenderness in legs, clients may be more comfortable with lighter pressure.
- Some clients use foam rollers and other tools with deeper pressure to reduce fibrosis in their legs.
- ✔ If clients have swelling, lymphatic drainage massage may help reduce pain and edema.

Dr. Andrea Brennan, Post-Professional Doctor of Occupational Therapy and Certified Lymphedema Therapist, works with lipedema clients. She recommends therapists interested in using deeper techniques with lipedema clients inform them of the rationale and potential outcome. Furthermore, listening to the patient, following their lead as it relates to the location of pain and their ability to tolerate such treatment is of the utmost importance. Her patients have had success in reducing their pain levels after deeper treatment like IASTM, Gua Sha, and treatments that use negative pressure and vibration. Find Andrea Brennan on Facebook at https://www.facebook.com/lymphedematraining. Quadrivas massage is a style of massage predominantly practiced in the Netherlands that claims to cure lipedema. Dr. Karen Herbst has conducted a small study of this treatment in the US. We will certainly be hearing more about this style of massage in coming years. Find out more at the Quadrivas website here: http://www.quadrivas.nl/en/quadrivastherapy/

What Is Happening in the Body

Lipedema can cause many complications including gait and postural changes, specifically valgus deformity, restricted ROM of knee and flat feet. There may also be hypermobility, pain, bruising, psychosocial issues, shortness of breath and an inability to find workout clothing. Arthritis can also come into play as the disease progresses.

Herbst (2012) found that "the excess tissue fluid weakens nearby structures leading to the development of joint pains; with progression of lipedema, arthritis develops" (Herbst, 2012).

Canning and Bartholomew (2017) state that "complications are both medical and psychological. Medical complications include joint problems involving the hips and knees that can lead to difficult and painful walking" and "psychological problems include low self-esteem, anxiety and depression" (Canning & Bartholomew, 2017).

Possible Lipedema Complications:

arthritis of knees	pain
bruising easily	psychosocial issues
flat feet	restricted ROM of knee
gait and postural changes	shortness of breath
Joint pain	valgus deformity
hypermobility	inability to find workout clothing

According to Langendoen et al. (2009), people with lipedema 'type rusticanus Moncorps' display "the frequent presence of knock knees, flat feet and moderately impaired calf muscle pump function (venous return)" (Langendoen et al., 2009). Jagtman, Kuiper, & Brakkee (1984) found that people with lipedema typus rusticanus Moncorps have a "skin elasticity deficit of the skin of the calf" partially due to swelling in the calf and also because of "a connective tissue defect of the fascia of the muscular compartment" (Jagtman et al., 1984).

Each client will be different, try the techniques you know to treat these issues with curiosity and solicit feedback from your client. Remember that some clients will bruise extremely easily; even brushing against a chair or table may result in a bruise for some.

What Are These Medications on Their Health Form? Information on Supplementation

What are all these supplements on your client's health history form? Find more about supplements for lipedema that Dr. Herbst recommends here: http://treat.medicine.arizona.edu/sites/treat.medicine.arizona.edu/files/medicine-and-supplements-handout-fdrs-2016_without_color.pdf, the book Lymphedema and lipedema nutrition guide: Foods, vitamins, minerals, and supplements by Ehrlich et al (2016), and Deborah Cusack's supplement protocol for clients with Ehlers Danlos Syndrome here: https://youtu.be/eZJR3d3Wwv8.

Let me be very clear - I have no expertise in advising clients on supplementation, so I am not recommending these protocols. I am passing on this information so Massage Therapists can be informed about the supplements their clients may be using to treat themselves.

Visual Resources for the Massage Therapist:

Photos of lipedema from the Lipedema Foundation: https://www.lipedema.org/photo-gallery and Fat Disorders Resource Society: https://fatdisorders.smugmug.com/

Photos of lipedema and hypermobility from the Milken Institute in the publication 'Lipedema: A Giving Smarter Guide.' http://www.milkeninstitute.org/publications/view/846

Resources:

- Canning C., Bartholomew J. (2017 Nov. 16) Lipedema. Vascular Medicine Vol 23, Issue 1, pp. 88 - 90 https://doi. org/10.1177/1358863X17739698 Retrieved from: http://journals.sagepub.com/doi/10.1177/1358863X17739698
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- Herbst K. (2012, February 3). Rare adipose disorders (RADs) masquerading as obesity. Acta Pharmacologica Sinica volume 33, pages 155-172 (2012) doi:10.1038/aps.2011.153 Retrieved from https://www.nature.com/articles/aps2011153#bib112
- Jagtman, BA & P Kuiper, J & Brakkee, AJ. (1984). Measurements of skin elasticity in patients with lipedema of the Moncorps "rusticanus" type. Phlébologie. 37. 315-9. Retrieved From: https://www.researchgate.net/publication/16702574_Measurements_of_skin_elasticity_in_patients_with_lipedema_of_the_Moncorps_rusticanus_type
- Langendoen, S., Habbema, L., Nijsten, T., & Neumann, H. (2009). Lipoedema: from clinical presentation to therapy. A review of the literature. British Journal Of Dermatology, 161(5), 980-986. http://dx.doi.org/10.1111/j.1365-2133.2009.09413.x Retrieved from: http://lipedemaproject.org/lipoedema-from-clinical-presentation-to-therapy-a-review/
- Lontok E., Briggs L., Donlan M., Kim Y., Mosley E., Riley E., Stevens, M. (2017). Lipedema: A Giving Smarter Guide. Milken Institute. Retrieved from: http://www.milkeninstitute.org/publications/view/846

About the Author:

Kathleen Lisson is Board Certified in Therapeutic Massage and Bodywork and is a Certified Lymphedema Therapist. She owns Solace Massage and Mindfulness, has taught classes at IPSB Massage College in San Diego and delivered the presentation 'Meditation and Mindfulness Interventions for Patients with Fat Disorders' at the 2018 Fat Disorders Resource Society conference.

Kathleen holds a Bachelors of Applied Science in Massage Therapy and is the author of 'Lipedema Treatment Guide' and 'Swollen, Bloated and Puffy, a Manual Lymphatic Drainage Therapist's Guide to Reducing Swelling in the Face and Body' as well as articles published in the Elephant Journal and the Labyrinth Pathways 10th edition. She has been quoted in the Prevention Magazine November 2016 issue and online in Bustle, Consumer Reports, Massage Magazine, Paper Magazine, Prevention and Runner's World.

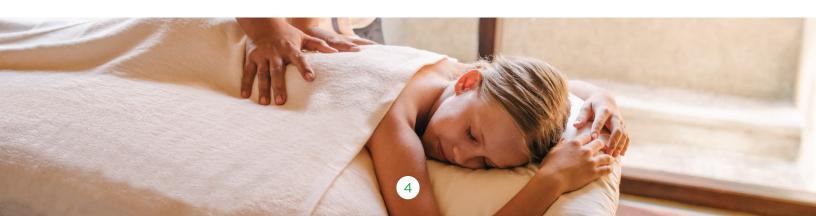
Social Media:

http://www.LipedemaTreatmentGuide.com

https://www.facebook.com/LipedemaTreatmentGuide/

https://www.instagram.com/kathleenlisson/

Massage Therapists: Reprint the final page in this guide and give this **FREE Resource Guide** to your lipedema clients - feel free to brand it with your own logo!



Lipedema Resources

"I can't seem to lose weight on my legs, no matter how much I diet."

"I can't find clothes to wear - I am different sizes on the top and bottom."

"My family tells me I have my grandmother's legs."

Sound familiar? If so, you may be suffering from lipedema, an adipose tissue disorder thought to affect around ten percent of the female population in America.

- ✓ Lipedema was first described by Doctors Allen and Hines of the Mayo Clinic in the 1940's.
- Almost 80 years later, the condition is often mistaken for obesity based on BMI and not well known in the medical community.
- For many people, lipedema fat (which is different from typical, healthy adipose tissue) starts appearing on the butt, thighs and calves at puberty.
- According to the Lipoedema UK Big Survey, the average age of diagnosis is 44 years old (Fetzer & Fetzer, 2016).
- Often, a diagnosis is only made after visiting a specialist like a plastic surgeon, dermatologist or vascular surgeon.

Resources:

Find other people with lipedema and ask questions about the condition in one of several Lipedema groups on Facebook. Lipoedema Warriors and Lipedema Sisters USA are two examples.

LipedemaTreatmentGuide.com offers resources and free newsletter

- ✓ Learn about self-care from this Jobst handout on Lipoedema
 http://lipedemaproject.org/wp-content/uploads/2016/02/2009_Jobst_Lipoedema.pdf
- ☑ There are several books on lipedema available on Amazon, including: *Lipedema The disease they call FAT: An overview for clinicians and the Lipedema Treatment Guide*

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