



# A PERSONAL TRAINER'S GUIDE TO LIPEDEMA

**By Kathleen Lisson, CLT**

Author, "Lipedema Treatment Guide"

✉ [LipedemaTreatmentGuide@gmail.com](mailto:LipedemaTreatmentGuide@gmail.com)

🌐 [LipedemaTreatmentGuide.com](http://LipedemaTreatmentGuide.com)



“

*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.*

”

**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.



10

## THINGS YOU NEED TO KNOW ABOUT LIPEDEMA

1

### What is it?

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

2

### When was it discovered?

It was first described by Doctors Allen and Hines of the Mayo Clinic in 1940.

3

### When is typical onset?

46% of women with lipedema symptoms said their symptoms started in puberty (Fetzer & Fetzer, 2016.)

4

### 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.

5

### Is there a cure?

There is no pill or operation that can instantly cure lipedema. It is a condition that needs to be managed to reduce severity of symptoms.

6

### 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.

8

### 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.

9

### 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)

10

### Is it caused by my eating habits?

No! Having lipedema is not your fault!

LipedemaTreatmentGuide.com

HERE ARE 5 WAYS TO IMPROVE YOUR WELLBEING

## Treatment Goals for Lipedema



### 1.) REDUCE PAIN AND INFLAMMATION

Gentle massage acts 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.

LipedemaTreatmentGuide.com

“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.”

Has a client ever come to you with these complaints? If so, they 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. Childbearing and menopause may also bring an increase in this type of fat, which is extremely resistant to diet and exercise. While some people are able to lose weight temporarily through diet and exercise, people with lipedema are unable to lose any lipedema adipose tissue.

Millions of people in America and around the world have been suffering since childhood with painful fat on their lower body that will not respond to any of the fad diets or punishing exercise regimes. Unfortunately, according to the Lipoedema UK Big Survey, the average age of diagnosis is 44 years old (Fetzer & Fetzer, 2016) and often, a diagnosis is only made after visiting a specialist like a plastic surgeon, dermatologist or vascular surgeon.

These facts set up the perfect storm for our client. She may have been suffering since childhood with painful fat on her lower body and all too often, advice from her health professionals, well meaning friends and family is just to diet and exercise. This is where you can make a difference! Movement and mind-body practices can help her to live a healthy and happy life.

As an **ACE-Certified Personal Trainer**, I would love to see my fellow Personal Trainers be able to confidently and knowledgeably be able to

- ✔ Inform clients with lipedema symptoms about the disease
- ✔ Keep clients safe and understand their unique needs
- ✔ Compassionately help clients with lipedema to find a movement program that works for them
- ✔ Implement a weight-inclusive and not a weight-normative approach

## Symptoms of Lipedema

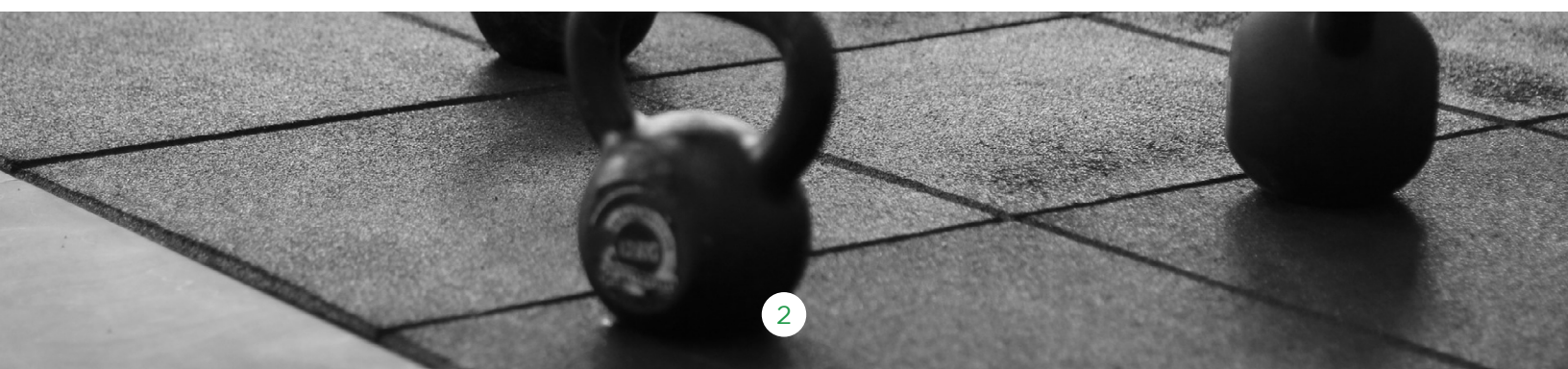
Lipedema is a word used to describe an adipose tissue disorder that is characterized by:

- ✓ Excess fat that collects on the lower half of the body.
- ✓ Fat that collects on both left and right legs equally.
- ✓ The lower body looks much larger than the upper body.
- ✓ The feet are spared, which may give the ankles a 'cankle' or pantaloons appearance.
- ✓ In 15 - 45% of cases, a family member is also affected.
- ✓ Skin may feel smooth or underlying tissue may have a nodular or beanie baby like feeling and in extreme cases feel like a walnut shell.
- ✓ Lipedema can also affect the upper arms and torso.
- ✓ There may be pain in the affected area when even light pressure is applied and legs bruise easily.
- ✓ Lipohypertrophy sometimes looks the same as lipedema, but the pain that happens with lipedema is not present.

Personal trainers, we have our work cut out for us in helping people with this disease. 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

## Compassion for Our Clients

Just thinking of the word exercise may bring back gym class memories, failed attempts at weight loss, painful workouts and feelings of shame and failure.

As Dana Schuster and Lisa Tealer share in their article ‘Exorcising the Exercise Myth,’ “the working-at-being-fat myth, held by most people, dictates that people get fat by choosing to avoid exercise in favor of sitting on the couch, eating donuts, and watching television; exercise is then the punishment, the penance, for this previous ‘bad’ behavior” (Rothblum & Solovay, 2009).

How can we be compassionate with our clients and make sure movement is seen as healthy and enjoyable part of life instead of a punishment or way to lose weight? How can we make a more compassionate environment for people of all sizes?

First, let’s look at the problem:

Angela Meadows, a researcher for the University of Birmingham puts it plainly in the title of her article ‘Discrimination against fat people is so endemic, most of us don’t even realise it’s happening’ which can be found here: <https://theconversation.com/discrimination-against-fat-people-is-so-endemic-most-of-us-dont-even-realise-its-happening-94862>

I have been thin all my life so I really didn't realize the extent of weight stigma in our society until I started researching about lipedema. Personal Trainers wanting to take a detailed look at weight bias can start by reading papers like 'How do obese individuals perceive and respond to the different types of obesity stigma they encounter in their daily lives? A qualitative study' which is available here: [https://www.researchgate.net/publication/51671809\\_How\\_do\\_obese\\_individuals\\_perceive\\_and\\_respond\\_to\\_the\\_different\\_types\\_of\\_obesity\\_stigma\\_they\\_encounter\\_in\\_their\\_daily\\_lives\\_A\\_qualitative\\_study](https://www.researchgate.net/publication/51671809_How_do_obese_individuals_perceive_and_respond_to_the_different_types_of_obesity_stigma_they_encounter_in_their_daily_lives_A_qualitative_study)

### **Here are some solutions:**

Linda Bacon suggests that we work to make our exercise spaces a “friendly, non-judgmental environment that acknowledges and celebrates body diversity message” in her Message for Fitness Professionals. Read it here: [https://lindabacon.org/HAESbook/pdf\\_files/HAES\\_Message%20for%20Fitness%20Profs.pdf](https://lindabacon.org/HAESbook/pdf_files/HAES_Message%20for%20Fitness%20Profs.pdf)

Dietitian and certified exercise physiologist Rebecca Scritchfield provides tips in the article 'Why we need to take fat-shaming out of fitness culture.' Read it here: [https://www.washingtonpost.com/lifestyle/wellness/why-we-need-to-take-fat-shaming-out-of-fitness-culture/2018/03/08/728365ac-1e31-11e8-9de1-147dd2df3829\\_story.html](https://www.washingtonpost.com/lifestyle/wellness/why-we-need-to-take-fat-shaming-out-of-fitness-culture/2018/03/08/728365ac-1e31-11e8-9de1-147dd2df3829_story.html)

### **Exercise for Clients with Lipedema**

Exercise is essential for these clients. Warren Peled & Kappos (2016) state that “low levels of physical exercise are a risk factor for further deterioration of lipedema ... the ultimate goal of therapeutic interventions is improving strength and fitness to enable an active lifestyle, which can help alleviate some symptoms, particularly in more mild cases” (Warren Peled & Kappos, 2016).

The ability to exercise may be limited by inefficiencies in the lymphatic system. Herbst (2012) recommended that treatment for the rare adipose disorder multiple symmetric lipomatosis (MSL) include low impact exercise to avoid “lactic acid accumulation in tissue due to poor lymph flow” (Herbst, 2012). I have also seen several people with lipedema that run and participate in sport regularly, so each body must be seen as an individual. There are no one size fits all diagnoses, symptoms, effects or treatment plans.



## Goals for Clients with Lipedema

We may also need to modify goals. Instead of losing inches and pounds, we can focus on activities of daily living (ADL) like walking longer distances (testing with a modified Rockport RFWT perhaps the 6MWT) , getting in and out of the bed/chair/car, and other issues important to the client.

What else can we focus on when it comes to caring for our clients? We can help in two ways - by creating an exercise environment that is not focused on weight loss and by shining the spotlight on healthy behaviors that have nothing to do with weight.

According to Tylka et al. (2014), a weight-normative approach puts the “emphasis on weight and weight loss when defining health and well-being” while a weight-inclusive approach puts “emphasis on viewing health and well-being as multifaceted while directing efforts toward improving health access and reducing weight stigma.”

The authors state that a weight-inclusive approach “challenges the belief that a particular BMI reflects a particular set of health practices, health status, or moral character” and recommended self-care behaviors include “eating nutritious food when hungry, ceasing to eat when full, and engaging in pleasurable (and thus more sustainable) exercise,” as well as adequate levels of sleep and hydration. Find more information on a non-diet way of eating in the IDEA Fitness Journal article ‘Health at Every Size: A Sound Approach to Behavior Change’ by Kirsten Acherman at <http://www.idealife.com/fitness-library/health-at-every-size-a-sound-approach-to-behavior-change>

The goal is to create a health care environment where clients feel less stigmatized (Tylka et al., 2014). Read the article ‘The Weight-Inclusive versus Weight-Normative Approach to Health: Evaluating the Evidence for Prioritizing Well-Being over Weight Loss,’ here: <https://www.hindawi.com/journals/job/2014/983495/>

## Lipedema and Muscle Strength

A Dutch study compared people with larger bodies to people with lipedema and found that those with lipedema had a slightly lower performance on the 6MWT and increased muscle weakness in the quadriceps. According to van Esch-Smeenge et al, (2017), “clinical examination of patients with lipoedema often reveals loss of muscle strength and exercise capacity compared to patients of similar size,’ posing a challenge to activity regimens” (van Esch-Smeenge et al, 2017).

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).

## Hypermobility

Another condition to consider is hypermobility. Some people with lipedema have hypermobile joints. How might this affect their exercise? Biomechanist Katy Bowman states that "hypermobility does not mean that you have long, loose muscles, but that a joint's ligaments are lax" and cautions that "people with hypermobile joints actually have very (very, very!) tight muscles" (Bowman, 2012).

Is stretching the answer? Hypermobile individuals may love to stretch, but may inadvertently overextend their joints during stretching. Bowman cautions that "those with hypermobile joints actually rearrange their bones to bypass the stretch" (Bowman, 2012).

Hypermobile clients may experience more fitness related injuries than the average population and may have less proprioception. They may benefit from learning and maintaining proper alignment during exercise and a focus on strengthening stabilizer muscles throughout the body. With all exercises, keep on cueing them on alignment so they do not daydream or zone out.

Learn more about working with clients with hypermobile joints in the Ehlers-Danlos Society webinar titled "Intelligent Exercise – How You Can Take Control With EDS" by Kathryn Lister, Associate Clinic Director with Physiotherapy Associates. The webinar is here: <https://www.ehlers-danlos.com/intelligent-exercise-how-you-can-take-control-with-eds/> I also recommend Sharon Goldman's IDEAfit article 'How to Handle the Hypermobile Client' <http://www.ideafit.com/fitness-library/how-to-handle-the-hypermobile-client>



## Addressing Activities of Daily Living

Another great way we can help clients is to guide them to improve posture and move more effectively. This will reduce the likelihood of injury and keep them independent. How do clients sit in a chair and then return to standing? How do they sit when they work at a desk or on their computer? How do they stand when doing chores or cooking tasks (balanced on both or just on one foot?).

Sometimes going over the fundamentals with a client can make everyday activities less painful! Sharing information like the tips in this hiking video by biomechanist Katy Bowman is a good start: [https://youtu.be/cDleu\\_QL51U](https://youtu.be/cDleu_QL51U)

Another great resource is “Spotting and Fixing Flaws in Walking Biomechanics,” by Justin Price, creator of The BioMechanics Method®. The article is available to IDEA members at <http://www.ideafit.com/fitness-library/spotting-and-fixing-flaws-in-walking-biomechanics> Price also offers a ‘Simple Visual Assessment for People with Foot and Ankle Pain’ at <https://youtu.be/Uwh35afMYFE>

## 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. Karen Herbst recommends here: [http://treat.medicine.arizona.edu/sites/treat.medicine.arizona.edu/files/medicine-and-supplements-handout-fdrs-2016\\_without\\_color.pdf](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>.

Carrie Myers shares information on how several popular medications can affect clients when they exercise in the ACE article ‘Common Medications and Their Effects on Exercise Response.’ Find it here: <https://www.acefitness.org/education-and-resources/professional/certified/may-2018/6992/common-medications-and-their-effects-on-exercise-response>

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 Personal Trainers can be informed about the supplements their clients may be using to treat themselves.

## How can personal trainers help clients with lipedema?

Exercise will not reduce lipedema fat, but movement throughout the day is essential for maintaining health. Exercise can reduce strain on and stabilise joints, increase lymphatic flow and have psychosocial benefits. Exercises that support the lymphatic system for lipedema clients include:

- ✓ Aerobics - make sure your client's muscles do not 'feel the burn,' unless they know they can recover well. Focus on joint movements but protect their knees from overuse.
- ✓ Aquatic exercise and Water Aerobics - exercising in water will help the lymphatic system while your client gets a great workout.
- ✓ Belly Dancing - this form of dance has benefits for our bodies and it helped me see how beautiful my body is.
- ✓ Cycling - whether on an indoor bicycle or outdoors on a bike, cycling is a good low impact exercise.
- ✓ Dancing - rhythmic whole body exercise that is easy on the knee joints is a good option. Do your client's ancestors have a style of dance native to their culture? Exploring dance traditions from different cultures can help them find movement that speaks to their soul and represents their history.
- ✓ Elliptical machine - another option for a good low impact workout. I have heard of people using an under-the-desk elliptical machine at their desk to keep their ankle and knee joints moving while sitting for long periods at work.
- ✓ Hypoxi - a specialized workout that has worked for some people with lipedema. Read about some unofficial research here: <https://www.hypoxi.com.au/hypoxi-lipoedema-study-results/>
- ✓ Lymphatic focused exercise - I have seen a few styles of gentle movement that focus on getting the lymphatic system moving. Lebed and Tripudio are two types.
- ✓ Pilates - a popular workout, clients need modifications to ensure they are working out aerobically (avoid the burn if you need to) and their knees are protected from overuse.
- ✓ Rebounding - people with both lymphedema and lipedema can benefit from gently bounce on a rebounder, which is a small trampoline with a safety bar / handrail. The

movement of the ankle and knee joints and contraction and relaxation of the calf muscles help move lymphatic fluid out of the legs and feet. This may reduce swelling in the legs, ankles and feet. Clients should aim to bounce as many times as possible per minute - smaller bounces and steady movement are the key.

- ✔ Resistance Band Exercises - resistance bands are a good start for including body weight exercises in your workout.
- ✔ Scuba Diving - JJ Wheaton has lipedema and Dercum's disease and she has found pain relief by scuba diving, likely because of the increased compression of the deep water.
- ✔ Stretching - prolonged stretching will assist lymphatic flow.
- ✔ Swimming - a great form of exercise. Some people with lipedema find that swimming is easier with swim fins.
- ✔ Tai Chi and Qi Gong - excellent low impact for of exercise, just be sure to minimize deep knee bends.
- ✔ Whole Body Vibration - vibration plates really work to improve the body and reduce swelling. It can be complicated helping a client choose which style to use. Watch the video 'Pumping, Vibration, and Dry Brushing #FDRS2016' for some expert advice from Certified Lymphedema Therapist Molly Nettles. [https://youtu.be/e\\_RULqEPJxM](https://youtu.be/e_RULqEPJxM)
- ✔ Walking and Nordic Walking - excellent low impact exercises. Make sure the client has proper footwear that supports their feet, especially if they have flat feet. ACE Certified Exercise Instructor Jeanette DePatie DePatie's offers a great beginners walking program in her book, The Fat Chick Works Out.
- ✔ Weight lifting - A great way to build muscle, keeping in mind that feeling a burn in the client's muscles may indicate inflammation. A good option is to start with bodyweight exercises with exercise bands.
- ✔ Wheelchair exercises - Certified Lymphedema Therapist and Yoga teacher Sarmita Misra let participants at the 2018 FDRS Conference in a seated yoga practice. The video is here: [https://youtu.be/\\_2DOzxgnBGo](https://youtu.be/_2DOzxgnBGo) I love how she uses twisting and rotational movements to stretch the fascia. A similar style of yoga may work well for wheelchair bound clients.. Check my website at [LipedemaTreatmentGuide.com](http://LipedemaTreatmentGuide.com) for more resources.

✔ Yoga and Lymphatic Yoga - Shoosh Lettick Crotzer has a complete full body 'lymphatic flow' gentle exercise video here: <https://youtu.be/8btp39n5luc>

Intense exercise may increase swelling in these clients, and personal trainers and coaches should be sure to emphasize that these exercises will not reduce weight or cure lipedema.

Often, the most valuable thing we can say to our clients on that first visit is that they are not crazy and it is not their fault. They will likely have tried and failed to diet away the weight for years if not decades. Exercising may have resulted in changes in their upper body but no fat reduction in their lower body.

If clients cannot undergo liposuction treatment to remove lipedema adipose tissue, giving them the tools and support they need to add healthy exercise to their life, combined with conservative treatments like compression garments, dry brushing, manual lymphatic drainage massage, and self massage may make it easier for them to live with lipedema.

## Visual Resources for the Personal Trainer:

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>

More detail on the need for a weight-inclusive instead of weight-normative approach is at <https://www.hindawi.com/journals/job/2014/983495/>

## Conclusion

Your help and encouragement may delay or prevent the progression of this disease and give your clients years of improved mobility and quality of life. Thanks so much for the work that you do!

## Resources:

Bowman, K. (2012 Feb. 20). Hypermobility. Retrieved from:

<https://nutritiousmovement.com/hypermobility/>

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>

DePatie, J. L. (2011). *The fat chick works out!: Fitness thats fun and feasible for folks of all ages, shapes, sizes, and abilities*. Los Angeles, CA: Real Big Books.

Fetzer A. & Fetzer S. (2016). Lipoedema UK Big Survey 2014 Research Report.

Lipoedema UK. Retrieved from <http://www.lipoedema.co.uk/wp-content/uploads/2016/04/UK-Big-Surey-version-web.pdf>

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](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>

Rothblum, E. D., & Solovay, S. (2009). *The fat studies reader*. New York:

New York University Press.

Tylka T, Annunziato R., Burgard D., Daniélsdóttir S., Shuman E., Davis C. & Calogero R. (2014).

“The Weight-Inclusive versus Weight-Normative Approach to Health: Evaluating the Evidence for Prioritizing Well-Being over Weight Loss,” Journal of Obesity, vol. 2014, Article ID 983495, 18 pages, 2014. <https://doi.org/10.1155/2014/983495> Retrieved from: <https://www.hindawi.com/journals/job/2014/983495/>

van Esch-Smeenge J., Damstra R. & Hendrickx, A. (2017). Muscle strength and functional exercise capacity in patients with lipoedema and obesity: a comparative study. Retrieved from: [http://lymphoedemaeducation.com.au/wp-content/uploads/2017/06/1.-jol\\_12-1\\_27-31\\_vanesch-1.pdf](http://lymphoedemaeducation.com.au/wp-content/uploads/2017/06/1.-jol_12-1_27-31_vanesch-1.pdf)

Warren Peled, A., & Kappos, E. A. (2016). Lipedema: diagnostic and management challenges. International Journal of Women’s Health, 8, 389–395. <http://doi.org/10.2147/IJWH.S106227> Retrieved from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4986968/>

## 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, is a MMI (McLean Meditation Institute) Certified Meditation Teacher, ACE-certified Personal Trainer and RRCA Certified Running Coach.

Kathleen is the author of 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/>

I do not endorse or encourage the use of words “overweight” or “obese”, because they stigmatize people at the higher end of the weight spectrum. I believe that body sizes are naturally diverse, and that there isn’t anything inherently wrong with having a larger body. I may have used these words in prior materials before recognizing how harmful these words are to larger bodied people. I no longer use them as standalone terms. If I use them, I will clarify them by saying “overweight as defined by BMI.”

There will be times when websites or research is shared that uses these words, and I want to be clear that I do not endorse the use of these terms.

In addition, I will use the term, “fat”, as a neutral descriptor and not as a pejorative. I do this to normalize it as an adjective, such as, tall, short, or thin. I have adopted these beliefs from the fat acceptance movement which began in 1967.

I believe that the more we move towards fat acceptance the better understood fat tissue disorders will be and therefore, useful and effective treatment will be more available to people with lipedema.

Personal Trainers: 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](http://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](http://lipedemaproject.org/wp-content/uploads/2016/02/2009_Jobst_Lipoedema.pdf)

- ✔ Find healthcare professional using the Lipedema Provider Directory  
<http://lipedemaproject.org/lipedema-lipoedema-lipodem-provider-directory/>

- ✔ 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*

10

## THINGS YOU NEED TO KNOW ABOUT LIPEDEMA

1

### What is it?

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

2

### When was it discovered?

It was first described by Doctors Allen and Hines of the Mayo Clinic in 1940.

3

### When is typical onset?

46% of women with lipedema symptoms said their symptoms started in puberty (Fetzer & Fetzer, 2016.)

4

### 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.

5

### Is there a cure?

There is no pill or operation that can instantly cure lipedema. It is a condition that needs to be managed to reduce severity of symptoms.

6

### 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.

8

### 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.

9

### 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)

10

### Is it caused by my eating habits?

No! Having lipedema is not your fault!

LipedemaTreatmentGuide.com

HERE ARE 5 WAYS TO IMPROVE YOUR WELLBEING

## Treatment Goals for Lipedema

### 1.) REDUCE PAIN AND INFLAMMATION



Gentle massage acts 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.

LipedemaTreatmentGuide.com