

# Jeans on a Beach Day

**Susan O'Hara**

Foreword by Brenda Viola

*Note to the Reader:* LegsLikeMine and Susan O'Hara are not medical professionals and any advice shared in this book, on any of our web presence or social media is opinion, shared for entertainment and novelty only, and is based on personal experience as a patient with lipedema and lymphedema. Check with a doctor who is trained in and familiar with your particular condition and lipedema, on any exercise, product, treatment, diet or supplement/medication recommendations before starting or modifying these items for yourself. And if your doctor doesn't know about lipedema, please help educate her. And if she doesn't support you, or fat shames you, find a new doctor. Reliance on the content of this book or any portion thereof is solely at your own risk.

You are not alone! With millions of women in the world having lipedema, it's time to receive the care and products we need to live our best lives.

Cover art and editing by Rob O'Hara  
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**[www.legslikemine.com](http://www.legslikemine.com)**

Library of Congress Cataloging-in-Publication Data

Names: O'Hara, Susan, 1973-, author.

Title: Jeans on a Beach Day / Susan O'Hara

Description: Oklahoma City: 2022.

Includes bibliographical references.

Identifiers: ISBN: 9798443835211 (paperback)

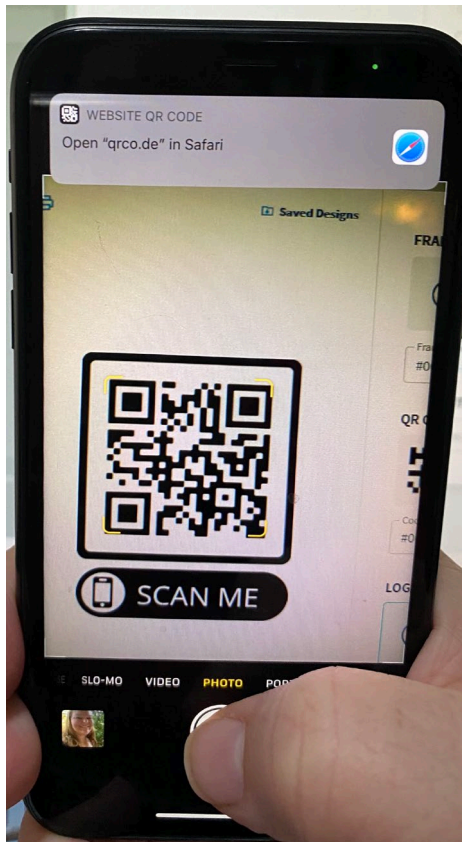
Subjects: BISAC: HEALTH & FITNESS / Diseases / Lymphatics / Lipedema MEDICAL / Public Health | HEALTH & FITNESS / Women's Health / Mental Health

Independently published.

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The author, modelling her lipedema-friendly outfits on [legslikemine.com](http://legslikemine.com).

To my mother,  
who weighed 100 lbs, and still ate only a boiled egg and tea every  
day in high school to try to get her legs to fit in  
with the rest of the girls.

For all of the women wondering what is wrong with your legs,  
it's not your fault.

With special thanks to our courageous contributors  
and the online lipedema community



This is Debra, one of our courageous and beautiful contributors.  
You are not alone.

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# Foreword

## by Brenda Viola

You know someone with lipedema.

You must, because it is estimated that 11% of adult women worldwide have this adipose tissue disorder. You may have noticed disproportionate fat “shelving” in the hip area; column-like legs that easily bruise; or cuffing at the ankles. Walnut-size fatty masses in the skin due to underlying fat nodules have changed the texture of their skin. Once you are aware of the signs, you see them everywhere.

I “discovered” lipedema in early 2020. As the marketing lead for Lympha Press, I had spent eight years marketing our pneumatic compression devices to those who treated lymphedema. When our newest device, the Optimal Plus, was cleared by the FDA for the treatment of lipedema, I knew I needed to learn more. Not about the FDA indication, not even about the studies that supported its use.

I wanted to find out about this condition and the women (for it primarily and overwhelmingly impacts women) impacted by this disease. Surfing the internet, which is how many of these patients find answers, I discovered amazingly resilient social influencers who were not allowing lipedema to define them. They were claiming their own worth and finding solutions to manage this condition.

What I heard over and over is “We’ll do anything to not get worse.” And they’ll try anything to get better – often spending inordinate amounts on compression, vibration plates, diets, and supplements, because many lipedema treatments are not covered by health insurance.

When my research shifted from my head to my heart, I was determined to actually trial our Optimal Plus to obtain candid feedback and real life results. Bottom line? If it was really going to help, I wasn't going to be responsible for selling a pipe dream.

Instead, the trials proved so successful, it opened a completely new avenue to help people through Lympha Press. And, along the way, I acquired more knowledge – and passion – to help these patients.

Lipedema is relentless. It most commonly presents at hormonal junctures like puberty, pregnancy, or perimenopause. Fat nodules appear and are not a result of poor diet or lack of exercise. Some of these women become near anorexic they are so desperate for their condition to improve. Along with the disproportionate size that accompanies lipedema comes diminished mobility, and pain. Some describe it as a dull, ever-present ache; others shrink from touch because it is uncomfortable.

Then there is the emotional pain that exacts an unseen toll. Cruel comments suggesting laziness or overindulgence sting. The fear of being rendered wheelchair-bound or suffering a fall they can't rise from hangs over them like a cloud. Bracing against an exuberant child's leg hugs or needing to purchase an extra seat for flight travel can induce shame, depression, and a host of dark feelings.

That's why the various communities that have been birthed in recent years are a lifeline, offering platforms of acceptance, encouragement, education, and inspiration to their followers. I'm honored to host the Lipedema Patient Roundtable every month featuring bright and brilliant voices that dispel the darkness.

It has been my privilege to also conduct one-on-one interviews with lipedema leaders. Every person's story is worth telling, and in the telling there is often recognition and the offering of hope – and help – that can be life-changing for these women.

Susan O'Hara is one of the women who shines as a light in this community. Her story deserves to be told and I know, will help many.



This is Mina, one of our courageous contributors. She is built like us and is so fashionable! You are not alone and you are beautiful.

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## **The Online Lipedema Community Replied to the Question, “What is One Thing You Wish You Had Known Earlier about Lipedema?” Here is What they Said.**

*“That it's not my fault; that BMI does NOT equal health or worth, and that appearing "healthy" is not a social obligation. If I'd been raised with those values instead of "Fat = abhorrent" my lipo-lymphedema wouldn't have progressed anywhere near the point that it's at now...”*

*“Considering how much dieting and extreme restriction messes with hormone levels I really wonder what I'd look and feel like if I'd never been forced into a cycle of disordered eating and over-exercise as a child. It stuck with me through my life and did irreparable harm.”*

*“I wish I had known how much processed foods cause inflammation & exacerbate my condition.”*

*“I wish I knew how important compression was to wear all the time.”*

*“That it is hereditary.”*

*“Mostly that it was even validated as a disease. We've all heard, you're just fat, you need to lose some weight and it will get better.”*

*“That it's not my fault.”*

*“I just wish I knew earlier.”*

*“I wish I had known what I had earlier to prevent progression, start compression early and do liposuction before getting to this point! I wish I could have helped my daughter before she progressed to the point she is at.”*

*“Just why my legs looked different as soon as I went to school and saw other girls' legs.”*

*"I wish my mother knew about lipedema. She passed away a month before I learned about it."*

*"That it was an actual condition!"*

*"That I'm still beautiful no matter what the scale says and I have to train my eyes to see me the way God sees me, not the way man sees me."*

*"Surgery was possible. It would have helped my self-image."*

*"That it was a real condition...that it wasn't my fault."*

*"I wish I knew it was actually a thing. So many doctors seen, and symptoms that were overlooked or ignored."*

*"I wish I had known 30 years ago."*

*"That there is surgery to help us. I didn't learn about it until age 62. I would have had surgery earlier in my life."*

*"I wish I'd known 20 years ago and gotten it under control with conservative methods when I was much younger...I wish my grandmother and mother had known about it 70 years ago. Might have stopped the family cycle of negative self-image and horrifically damaging yo-yo dieting that let me to my first WW meeting at 11 years old."*

*"I wish I'd known what it was. It took me until I was 60 to be diagnosed. I'm stage 4 now."*

*"That it wasn't my fault. I failed to lose weight on my hips and legs. I gave up every time I went on a diet because my heart sank every time the results never showed, compared to my effort."*

*"That it wasn't my fault. Even though I know this now, I still find myself trying to blame myself, like I could have prevented this. It's hard work to change 30+ years of thinking."*

*"I wish I would have known that I'm not special and that it would get worse, much worse. I guess I was just in denial because it's hard to picture yourself that way."*

*"I just wish I'd known about it earlier and have been able to try to control it sooner."*

*"I discovered it by accident about 2 years before my diagnosis and just thought it was easier to work out with compression."*

*"I didn't even know what lipedema was! I thought I had severely fat legs and a big bum that wouldn't go away. One day I happened to see a post on Pinterest about lipedema and was fascinated. It was me to a "T." After that I couldn't stop researching and am still on that journey! I'm 71 now, and don't know if I'm a good candidate for surgery at this point, but I sure would have jumped at the chance to have surgery in my younger years, had I known about it."*

*"I wish I would have known it was a medical condition, and I wasn't just weak, lazy and fat."*

*"That I'm not alone and that more doctors know what it is."*

*"It isn't my fault and I'm not alone. I would have given myself grace and confidence that I didn't have until recently. It can be a lonely disease."*





## JEANS ON A BEACH DAY

*"I didn't even know what lipedema was! I thought I had severely fat legs and a big bum that wouldn't go away. One day I happened to see a post on Pinterest about lipedema and was fascinated. It was me to a "T." After that I couldn't stop researching and am still on that journey! I'm 71 now, and don't know if I'm a good candidate for surgery at this point, but I sure would have jumped at the chance to have surgery in my younger years, had I known about it."*

*~ Member of online lipedema community*

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# Chapter 1: Why do You Have This Book in Your Hands Today?

*“There once was a girl that was carefree and loved life. She was fearless and lived with a wild abandonment. She rode horses bareback, ran through the woods, and rode bikes like the wind. That is until she turned 12 when hormones kicked this disease into overdrive. That girl still lives inside of me, trapped behind the prison bars of Lipedema.*

*The symptoms that I've had to deal with over the years started with unexplained weight gain, weight not coming off my hips and thighs no matter what I did. Sure, I was able to lose a bit here, but it reappeared with a vengeance. This turned into joint wear and tear. As this progressed, I also had added fatigue especially when it came to working out. I never seemed to be able to progress working my muscles fully. My legs hurt even to have a blanket on them. They would swell painfully but the swelling never affected my feet. I also started getting cellulitis for no apparent reason. My blood work always came back as puzzlingly normal.*

*Later, I was convinced that I was just overweight and needed weight-loss surgery. I was worried about the full anatomical, so I chose to instead do Lap-band. I thought this would be a life changing experience and it was just not in the direction that I had wanted. After the surgery I watched pounds melt away from people in the support groups that I was in which I at 800 calories a day and did 2 hours of strength training and 4 hours of cardio each day to barely be able to lose 1 to 2 pounds a month. The weight I was able to lose was in places such as my face and chest. This inflammation caused by an allergy kicked the lipedema into hyper drive.*

*A year after surgery, I found that I couldn't stand on my own or barely walk across a room by myself without help. I hurt all over, I wasn't sleeping, and my size kept growing. I did research on “silicon leaking” and found that I had all the reaction symptoms. It took me a year and a half to get the band removed, by then though the damage was done. During this time of trying to figure out what was wrong though a Physical Therapist that had trained in Germany, I was diagnosed with Lipedema.*

*Conservative treatments have been supportive but when I started losing my mobility, I opted for surgical intervention to try to ensure that my mobility stays intact. It is so easy for Physicians to look at us and not see a chronic disease. This disease steals our lives from us just as so many of the other chronic diseases do. My hope is that someday this mind set will change, and this disease recognized so that others won't have to endure what so many of us have.” ~ Debra, courageous contributor*

Hi, beautiful! I see you at the beach today wearing jeans while everyone is out playing in the water, wearing that long dress when everyone else is in knee length skirts and shorts, or covering yourself with a flowing caftan in order to hide your bare legs in a swimsuit. And I see you, too, walking around the theme park with swollen legs that pain your every step.

I want you to know right now that you are not alone and that millions of women like you have legs that are inexplicably larger than the rest of them. For many of us, we have a disease called lipedema that is hereditary, and not our faults. I wrote this book so women who don't know about lipedema would be aware of the disease and have some ideas on ways to get it treated and to get support, because lipedema can get worse and even cause immobility.

I have memories as an overweight teenager of opening the mailbox one day and finding a handwritten envelope addressed to me. I was absolutely devastated when I opened the envelope to find someone had mailed me a clipping from a magazine ad for a weight loss program. I remember how embarrassed and pained I was that someone could be so cruel as to take the time to shame me this way, in the privacy of my home where it was safe to be myself all of the time.

Fast forward nearly forty years and I've discovered that my inability to lose weight is actually because of a genetic disease called lipedema that affects my arms, legs, hips, rear end, and stomach. I've had bariatric surgery twice and done 'all' the weight loss and exercise programs out there without success in reducing these body parts. Just a few years ago, by luck of the fates, a medical professional recognized a symptom that led me down the path of discovering I had lipedema. This was after years of covering up my body, trips to the doctor for leg and knee pain, MRIs, x-rays, and blood tests without answer. Since my diagnosis, I've been able to meet with professionals who help me to manage my condition. I have even been fortunate enough to have three surgeries with a specialist who is dedicated to helping women like me. Additionally, I've met other women in my tribe who are in various stages of the lipedema journey, and have been able to share my story with thousands of them in hopes that they might use what I've learned to manage their conditions more quickly.

To spread my message, detail my treatments, and document what I've learned along my own personal journey with as many people as possible, I've established a website and social media presence called [LegsLikeMine.com](http://LegsLikeMine.com). Having to figure things out for

myself has been very challenging, and I don't want you to have to go through that. This book includes answers to questions I repeatedly receive from women daily. I've answered thousands of emails and messages to help others navigate this disease we didn't deserve and don't want.

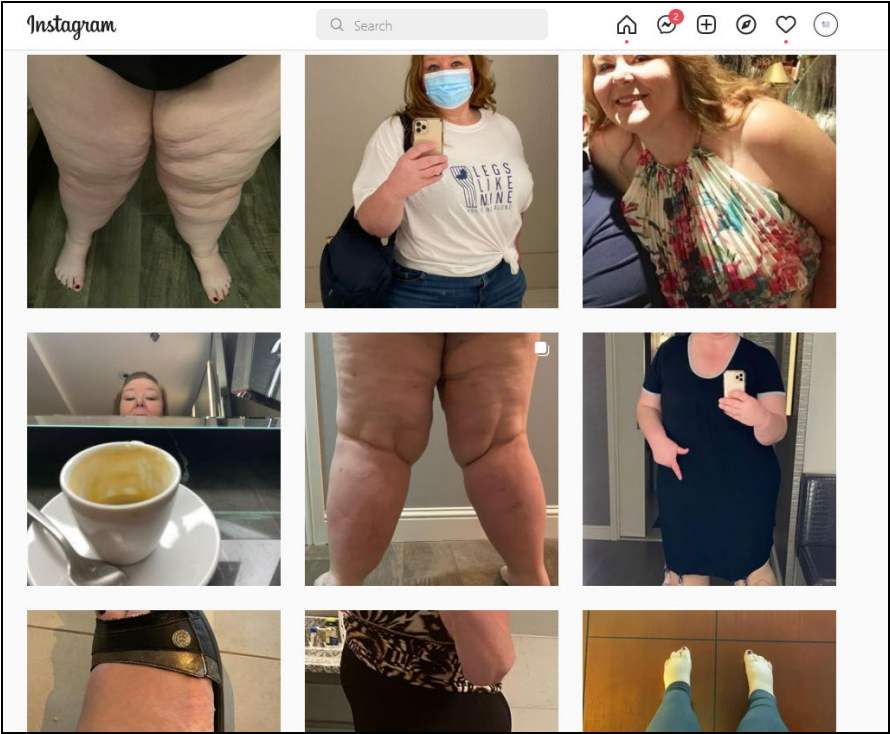
This book was written specifically for women who either just learned about lipedema and are looking for next steps and resources, or for women who have never even heard the word lipedema but may be showing the outward signs of having the disease.

Please don't be offended or pained like I was if someone gifted you this book -- consider it an act of love that might prevent years of suffering and wondering what's wrong with your legs, or why you can't lose weight in your hips after all kinds of diet, exercise, and maybe even bariatric surgery.

On social media, I participate in all kinds of online forums and support groups for women with lipedema and lymphedema. We often have the discussion about what to do in situations where we see someone hiding their legs, who have unusually big legs or other symptoms. Should we tell them and risk embarrassing them? The answer goes back and forth. Some of us would be mortified if a stranger approached us in this fashion. But most of the women I polled said that they wish they'd known earlier so they could get treatment and not feel like they're a freak, or alone - the only one suffering with legs that just don't make sense.

Should this happen to you, I beg you to be thankful to the person who had the courage to give you this book. That person wants you to have a chance at keeping your mobility, feeling less pain, and even, yes, looking more normal. It was an act of love. If you didn't know about lipedema, it might be worth looking into with a knowledgeable doctor. If you already knew of lipedema, maybe you'll get a golden nugget of information that can help you, a friend, or your daughter manage it as well. And hopefully you can connect with those of us participating in support groups and social media sites to know that you're part of a community that is willing to help, provide advice, and support for people with legs like ours.

And if you bought this book for yourself, congratulations for having enough love and courage to try and figure out your own disease for yourself, for your daughters and your mother, who may also be suffering from lipedema.



A little peek at the LegsLikeMine Instagram page

## Chapter 2: My Story

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### Lipedema Patient Story – Liz



Susan O'Hara and her mom, Liz, age 73.

*"My mother has had lipedema in her legs since the onset of puberty. We didn't know this until two years ago, when I was diagnosed as well. Despite weighing around 100 lbs in high school, Mom went on a very restrictive diet for years, eating nothing but a boiled egg and tea each day. She passed out repeatedly during these years (even falling down an escalator once!), yet her legs remained unchanged. My mother's condition went undiagnosed. She's in her 70's now and isn't a candidate for surgery due to other health issues, but shares that if she were even ten years younger, she'd be having surgery and seeking treatment ASAP. My mission is to share about lipedema so that no one goes undiagnosed."*

~Susan O'Hara

It took me years of thinking I might have cancer before I discovered lipedema. Imagine the terror of wondering when it would take me.

I'm guessing so many of you have similar stories. For me, I've been overweight since about second grade, and suffered all the things that kids do to each other because of it. I was on the grapefruit diet by age eight. I was a pretty active and outdoorsy kid, but always the one wearing husky jeans. Years of different diets and shenanigans with my body left me, "done with it all" until I had kids. Or at least until I wanted to have kids.

My fertility struggle has to fit into this whole mix somewhere. For several years during the time I was trying to get pregnant, I went to several doctors for help. This time was incredibly difficult psychologically. I experienced numerous doctors who fat shamed me, told me I wasn't healthy enough to have a child, told me to lose weight, and even who told me that their medical equipment and speculums weren't long enough for me to be treated. So not only was I already self-conscious about my body, but I began to think of myself as not even a normal or real woman because I couldn't bear children. I eventually found a doctor at Bennett Fertility Center in Oklahoma City who not only recognized that I had polycystic ovary syndrome (PCOS), but was able to find the right treatment – the second month of seeing him no less – that helped me to get pregnant.

I left the hospital after delivering my first child with legs that would never be the same as they were before pregnancy. After several months on fertility hormones and then being prescribed progesterone for a total of 12 months during pregnancy, my legs had developed into tree trunks. With the birth of my second child, they grew even more. I continued to work full time in a professional management position while raising the kids with my husband. A few years later I noticed nodules that felt like painful golf balls under my skin as the stress in my job increased dramatically. I believed I was developing cancerous tumors in my legs.

I had natively started wearing maxi dresses to cover my legs, and had one day - years ago - decided shorts as a regular outfit piece weren't for me, and had also switched to wearing long men's board shorts over my bathing suit to hide the growing bulges. I felt jealous when I saw women my age, some of whom were bigger than me, who still had nice legs to show off when all I wanted was to cover mine to the floor. I somehow felt, 'less than,' because I couldn't get my legs under control, despite having bariatric surgery twice and losing more than 150 pounds, training and completing a

(walking) half marathon, and enjoying being an active mother I simply did not understand what was going on with my body.

My legs had been growing for a while and the backs of my calves especially got very hard and fibrotic - they even developed lumps so large that I'd named them. My primary doctor at home was very kind and worked with me extensively to try and figure out what was going on as each new symptom appeared. She sent me for x-rays, blood work, and several MRIs (both with and without contrast), but the results were inconclusive. The two of us had all but given up and explored alternatives including switching to a vegetarian diet for several years and even considered a third bariatric surgery which, I thankfully, decided not to do. Although they were well meaning, none of these treatments helped my condition. My legs continued to grow while I was a dedicated vegetarian! I saw a trusted physical therapist and even talked about 'Larry' (the name I had given to the large lump on my left calf), but neither of us knew what it was.

I suffered for years with legs that ached constantly and kept me awake at night. When my cats walked on me, it hurt deeply in my legs. I tried all kinds of things to help my legs: creams, ace bandages, icing, fascia blasting, rolling them with a rolling pin, special exercises and targeted weight lifting. Sadly the only results were wasted time and money, and a lot of strange bruises that looked like I had been beaten severely in the legs.

One day, I developed a sudden bout of tendonitis in my leg, rendering me nearly immobile, and I saw a foot specialist, who sent me to a brace company to have a special brace fitted before a trip to NYC with my Girl Scouts that would require miles of walking each day. I was only in my mid-forties and not ready to quit doing fun things like this. I was determined to use the brace and take the trip.

At the brace supplier, the technician casually asked me, "Who is treating your lymphedema?" Lymphedema? I had never heard of this word. It had a name? And there were other people around who were hiding their legs and suffering like me? Total lightbulb moment!

I went back to my doctor and reported what the brace technician had said. She immediately sent me to a certified lymphedema specialist for decongestive therapy. The therapist assigned me swimming therapy, arranged for a flexi touch pump, and taught me about wrapping and compression. I was angry at having gone years of not knowing that my condition was legitimate or special or real, but I was also relieved, finally, to have a sense of understanding about what was happening to my body. I had hope

that I could get the swelling down enough to maybe someday wear a pair of shorts again with some dignity.

I saw the therapist faithfully several times a week, was measured for compression, bought boxes and loads of wrapping supplies, started using my pneumatic pump daily, and began to see some difference in the size of my legs. The goal of all these treatments is just to reduce the swelling and inflammation, and then the compression was to keep it from coming back. I was to wear the wraps for 24-36 hours at a time and take them off only to shower or to be rewrapped. I really struggled with wearing wraps on my legs because they slide down quite easily, it's hard to walk with them on, and they're bulky, and so on. I ultimately opted to purchase Velcro ready-wraps from [lymphedemaproducts.com](http://lymphedemaproducts.com). The first ones I bought were customizable, and my therapist cut them down to fit for me. After I wore this type for a while, I discovered other wraps available on Amazon that were multiple layers of Velcro and could be adjusted each time they were put on. Also I was able to wear these wraps on top of leggings or compression, and I could move! Best of all, they worked to reduce swelling!

My new lymphedema diagnosis led me to join multiple Facebook support groups for lymphedema patients. Just when things were starting to feel better and I thought I was at the end of the line for treatment, my legs flared up with almost double the normal swelling and pain levels and went out of control, correlating with a ridiculously stressful day at work. In a single day, several new bumpy and painful golf ball sized nodules appeared out of nowhere. I went to every resource I knew, asking for help once again. When I shared photos of my legs online, I learned from some of my new friends that I may have actually had late stage lipedema (lipo lymphedema). Never having heard the word lipedema, I went down another rabbit hole of research and for the first time, I saw so many people with legs like mine on the internet! I immediately felt a kindred spirit with these brave souls who had shared their pictures and helped me figure it all out. It was the pictures that explained so much. Epiphany! Finally I had a term to Google, and a way to find specialists knowledgeable with the condition.

Through the internet, I connected with a doctor specializing in lipedema who looked at my pictures remotely and had me fill out a very extensive questionnaire, providing a very thorough history on my legs. After receiving my documentation, I met with the doctor and his staff over the phone to begin my journey toward treatment. Four years after I started my search in earnest, I finally received a

written diagnosis by Dr. Jaime Schwartz in California, halfway across the country. Lipedema.

Once I got the diagnosis, I moved extremely fast to get surgical treatment – I'm not getting any younger and I have so much to do! I switched insurance companies to one that is known to cover lipedema. I gathered all of my documentation of tests and scans over the years, my receipts from treatments and purchases to date, and got my package ready. I was approved for surgery in January 2021, and by mid-February 2021, I was laying on the operating table in Beverly Hills and had the first 16 litres of lipedema tissue removed. I go into a lot more detail of the insurance and surgery process for you further in this book. I also documented my surgical recoveries every step of the way on my YouTube channel ([youtube.com/c/LegsLikeMine](https://youtube.com/c/LegsLikeMine)).

As of today I've had three surgeries with Dr. Schwartz to help get my legs under control. In addition to surgery I continue to wear compression and wraps regularly, swim, and receive regular lymphatic therapy. Yes, my legs are still lumpy and bumpy, but they don't hurt as much as they used to. I wear swimming suits, shorts, and shorter dresses than I have in twenty years. Most importantly, I'm able to walk without pain again after years of suffering.

Another thing I do is feverishly overshare and receive support online with many women in various stages of the treatment and diagnosis journey. I feel very deeply that I, and you, need to do what we can to share our stories so other women can receive diagnoses in time to save their mobility and dignity.

Along my journey I've learned that millions of women have lipedema and that I'm not a freak or rarity, but part of a big percentage of the population. There is some debate about the studies, but several sources, including the National Institutes of Health website cite that 11% of women have lipedema. ELEVEN PERCENT.

Through becoming part of the lipedema community, I've accepted the condition I have and now believe that I do indeed fit in. And yes, I'm still pretty. It took a lot of time, but I'm at peace with where I am. I'm honestly just glad to know that I have a real disease and that I'm not a failure for not being able to get my legs to slim down through diets and exercise. I even feel like it's appropriate and right to continue doing things I love like snorkelling, playing on the beach, hiking and camping, and to show my legs more. It helps other women feel comfortable too when they see other imperfect people enjoying life. I plan to begin carrying little cards about lipedema that I can discretely share with women who look like me. I

know I would be forever grateful back in the day when I had no clue what was going on, to even know the word lipedema.

I hear over and over that doctors receive only one hour of training on the lymphatic system during medical school. My experience is that lipedema and lymphedema, while not rare, are very rarely diagnosed correctly. Diagnosing as early as possible is imperative to slow progression with conservative treatments. This is another reason why we need to be aggressively sharing the story. Many of us, including myself, had doctors who hadn't been trained to recognize and diagnose lipedema. Others, sadly, have doctors who diagnose it as obesity, and worse, some who fat shame. If we can get more doctors aware of the disease, we can get to needed treatment.

So as I mentioned, I decided to get courageous and share my story -- well, actually OVER share my story. I started adding pictures to Instagram and Facebook, began blogging on [LegsLikeMine.com](http://LegsLikeMine.com), and started educating any medical professional who touches me about my condition, including my dentist! I brought pamphlets to my doctor, let other doctors touch and feel my legs to understand the lipomas in them, and invited my occupational therapist to have her peers come and see me before and after surgery. I started referring other lipedema patients to my medical team, both at home and in California. Additionally, I answered (and continue to) thousands of emails and messages from desperate women, all searching for the name of their disease and a way to receive treatment, wanting to know what I've experienced, and asking for advice, help, or just a listening ear.

After answering many questions individually, but repeatedly to different people, (and with the guidance of my husband who is a prolific blogger), I learned that capturing my knowledge and experiences in blog format was a more efficient way to share the same information with multiple people asking the same questions.

I wrote this book to answer some of the same questions for you, in hopes that you might gain a golden nugget of information that helps you or someone you love manage their condition. I've included several resources throughout the book to help you connect with professionals, support groups, and researchers, so you can get educated and take action.

I also hope you will have courage and share this book with the lady you see wearing jeans on a beach someday, so that she might figure out what's going on with her own legs and give her the information she needs to be empowered to change her life.

## Chapter 3: Lipedema Basics

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### Lipedema Patient Story - Jana

*“My 3 year old nephew says, “you got big wegs,” as his mother quietly shushes him.*

*I’ve always had trouble with my weight. I have never been able to wear boots. My calves are too big. After three kids, I really let myself gain weight. In less than a year, I had a hysterectomy and papillary thyroid cancer. Not long after that I noticed my legs getting larger and really hurt when my nine pound cat walked across them. Diagnosed with venous insufficiency, I had my veins ablated. I remember asking my doctor if my legs would be less large and his answer was “possibly, but maybe not.”*

*Bruises were coming more easily and some have remained as a discoloring. Lumps could be felt throughout my legs and I have numbness. I decided to get gastric sleeve surgery in May 2021, and I started thinking wouldn’t it be great if I could wear boots. I started researching and realized my legs might not get smaller, I may have a disease, not just fat. I have lost 115 pounds and sure enough they have gotten smaller but not like my face, neck shoulders and upper torso.*

*I wanted to have an official diagnosis. I mentioned it to my primary care provider She tried to correct me twice, “You mean lymphedema.” Like so many other doctors, she had never heard of it. Neither had my endocrinologist. I chose Dr. Cobos, an endocrinologist in Laredo, TX after recommendations on Facebook support groups.*

*I got my medical records from my vascular surgeon less than a week before my appointment. On the way there, I started reading my records and was completely shocked to see in bold letters, “**Lipedema Bilaterally in Legs.**” He never told me that I had lipedema, even after asking if my legs would be less large.*

*Not only do I have lipedema in my legs, but also in my belly and my upper arms. I may not be able to get the surgery just yet, but at least I know it is not just fat “wlegs.”*

The most difficult thing about lipedema is that it's very often diagnosed as simple obesity by all kinds of doctors. Some are well meaning, and some are fat phobic and don't want to waste their time on a patient who appears to be lazy and non-compliant.

### **So what is lipedema anyway?**

Lipedema is a genetic disease that causes the body to distribute fat in an irregular way below the skin. It affects mostly women. Many doctors and researchers believe that with lipedema, fat distributes symmetrically between legs and buttocks, but many women also have it in different representations including their arms and bellies, and even asymmetrically

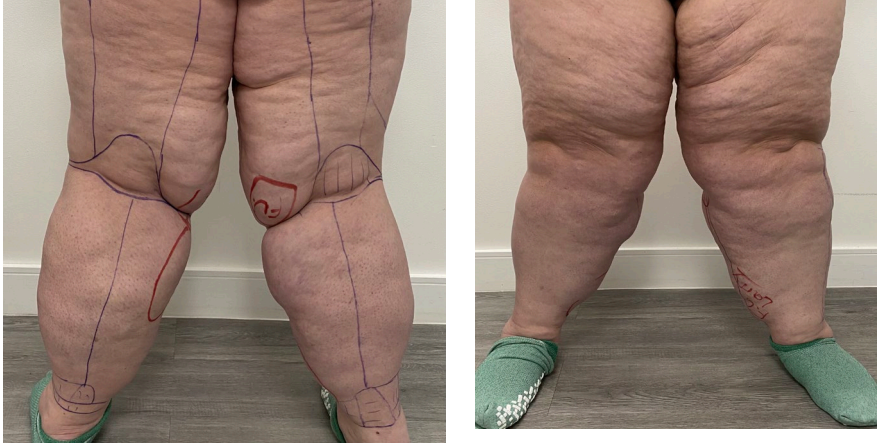
Symptoms of lipedema include having large legs that sometimes look like tree trunks and don't turn in towards the ankle like more typical legs. They can be lumpy or bumpy or hard and fibrotic depending on the level of lipedema. Some women just have big bums or very large arms. Some have big thighs with small calves, while others have big calves and small thighs. There are many types and stages.

Several really good websites like **[lipedema.org/about-lipedema](http://lipedema.org/about-lipedema)**, have fantastic amounts of research complete with pictures, and detailed medical information on the disease. Before you look at my pictures and decide you don't have lipedema because you're not shaped exactly like me, please visit these professional sites to see the types and stages of lipedema. The manifestation of the disease is quite diverse.



[Lipedema.org/about-lipedema](http://Lipedema.org/about-lipedema)

As lipedema progresses, the appearance of cuffing can occur by the ankles and even at the wrists, like folds of fat are hanging over the ankle and wrists. In later stages of lipedema, lymphedema can also develop and then leakage of lymphatic fluid happens, hard skin growths, and immobility occur due to the enormous weight of the overgrown lipidemic areas.



This is what my legs looked like prior to my first surgery, which was focused on the posterior legs. Most of the surgical time was spent on the hard fibrosis that had developed in my calves.

The following picture shows what my legs looked like on a trip to Savannah, GA prior to being diagnosed with even lymphedema, or having lipedema removal surgery. The left leg is definitely displaying more lymphedema, and the right leg has a pitting edema near the top of the calf. This was the trip where everyone began wondering, "What the heck is wrong with Susan's legs?" This was also the first time in my life I opted to not put on a swimming suit and get in the water. It's a really sad memory for me, even though I am walking down the streets of Savannah wearing a pirate hat!



The first day I opted to not put on a swimsuit in front of others. A sad day for me.

Other symptoms of lipedema include pain in the fat. For me personally, it hurt when I was in a seat that was even slightly too small, and sometimes even with just a seatbelt being on me. My legs and knees throbbed in bed every night. Another symptom is easy bruising. Many of us suffering with lipedema regularly develop ‘mystery bruises’ all over the affected areas. Being a very frequent traveller, I could always count on receiving mystery bruises on travel days, moving days, and sometimes even laundry days, and the bruises would last for weeks.

For many, we have lipedema nodules in the affected area. Mine varied in size; some were as small as grains of rice, with others larger than a golf ball. I had nodules in my calves, behind my knees, inside my thighs, and in my upper arms. My doctor eventually removed many of them with a special liposuction technique, but I still have several yet to be removed, and several still growing in size. Those nodules, again for me, were incredibly painful, and doctors could easily feel them by simple palpation. One of my nodules (the one named “Larry”) I felt was visible from across the street. When I see this picture now, I want to just grab the

massive fat pads inside my knees and pull them off. I wish it had been that easy!



"Larry," the ever-present and growing nodule inside my left calf. It swelled to 'amazing' proportions during times of stress and hurt deeply at night.

All of these areas are resistant to traditional diet and exercise. For many, again like me, bariatric surgery would take away the normal adipose/fat tissue, but the lipedema legs remain along with a disappointed patient who's more than likely gone through quite a bit to qualify for bariatric surgery, not knowing that a portion of her 'fat' is lipedema that will remain despite reduction in calories and smaller stomach size.

The next picture is a golf ball sized nodule (one of many) on the inside of my right knee prior to any surgeries for removal. The nodules on the inside of my knees called 'fat pads' are especially concerning. These pads push my knees outward. And with years of this occurring, it stretched the connective tissues in my knees permanently. My mobility was affected before surgery because they rubbed together, and hurt deeply – down to the bone. And after surgery, I now have the hypermobile knees due to the loose and stretched connective tissues. So after surgery my knees dislocate sideways quite frequently, especially when they aren't pushing directly down by my standing. So lipedema is a double whammy. Again, getting treatment early can help save the fat pads from growing, which helps the knee tissues from stretching, so you don't dislocate all the time.



A painful, visible and palpable golf-ball sized nodule inside my right knee.

The next picture shows what my legs looked like after I had had my first bariatric surgery and lost 167 pounds in 2007. By then I'd already had both of my children using fertility treatments and was age 34. I was eating very small amounts of only protein and walking up to fourteen miles a day to stay at this weight. My hair was falling out and I was perpetually fatigued. Also, I was a hungry mama and I really missed most of the food I used to enjoy, including even vegetables. You can still see quite a bit of fibrosis in my legs, and folds and fat pads in the knee area. I promise you, this is as skinny as my body can be. And it only lasted for a very short time as I could not continue starving and having to work out that much.



One thing to reiterate is that lipedema takes many forms. While it heavily affected my legs, arms, and belly, for some women

it manifests in the hips and buttocks only, or in certain areas of the legs and arms, or any combination of these. There are several websites, such as [lipedema.org](http://lipedema.org), that have fantastic pictures of different manifestations of lipedema. They also have a brochure that you can download or order for sharing with medical professionals and other women that describes lipedema. I've referred many people to this website and am so grateful for The Lipedema Foundation's work.

If you're like me and many women who suspect they have lipedema, you'll want to dig into the best research around. If there is one document I'd suggest throughout this whole book that you read, it would be the Standard of Care for Lipedema in the United States, designed to, "advance our understanding towards early diagnosis, treatments, and ultimately a cure for affected individuals." This is the ground-breaking consensus document, led by Dr. Karen Herbst, who is a premier researcher and speaker on lipedema. This document is the one that we can and should refer to when working with insurance companies and doctors when they need convincing that lipedema is real and needs to be treated properly and aggressively. I have a citation to it in the bibliography section of this book.

### **What causes lipedema?**

Known research is showing that lipedema rears its ugly head at time of hormonal changes in women and that it is indeed genetic.

Puberty, hormone ingestion, pregnancy, and menopause may trigger its onset, but allow me to reiterate that any woman suffering with lipedema did not do anything to cause it. For many sufferers including myself, stress (which releases cortisol into the system) can cause affected areas to flare up as well.

Within the last two years, doctors have begun publishing papers showing that research has found a genetic biomarker for lipedema. And once they've found the genetic cause, the next step is research on a medicine that can prevent or reverse the affects. If you or your daughters are suffering from lipedema, hang in there! In our lifetimes, there could be a medicinal cure and even prevention for the disease. Until that happens, we'll have to go with the treatments available.

I also wanted to share that the Fat Disorders Research Society (FDRS) has a selection of amazing videos that share presentations at their conferences on YouTube. If you really want to dig into the science behind lipedema, take some time to review the videos available. I recommend any video including Dr. Karen L. Herbst – she is a world renowned researcher on lipedema, who is

caring and compassionate in her patient treatment. Additionally, she has a way of using diagrams, images, and stories to talk about the development of lipedema in a way that most people can understand. I have a link to the FDRS website in the bibliography, but also, here is a QR code that will take you straight to their YouTube channel with all of these great videos that I've mentioned.



Fat Disorders Research Society YouTube Channel

If there's one thing you need to take away from this chapter, it's this: *lipedema is genetic*. Read that again, to yourself.

You did not cause your lipedema. You don't deserve it and you couldn't have prevented it. It is not your fault.



This is what my arms and legs look like after three surgeries, one of which included my arms. I will always have lipedema, but my ability to move and to experience less pain are so much better than prior to surgery. I still need to finish up the surgeries including removing abdominal lipedema, in hopes it will relieve pressure from lymphatics in my legs and reduce lymphedema.

## Chapter 4: The Downside of Misdiagnosis and Delays in Treatment

*"I wish I'd known that lipedema existed, and that dieting/food restriction/excessive exercise and hormonal changes can exacerbate/accelerate it.*

*I also wish ANYONE had told me it was OK to self-advocate and tell weight loss pushers to sod off."*

*~ Member of online lipedema community*

Remember the tale of the frog in boiling water? When the frog jumped into the pot the water was cool, and because the water was slowly heated, he didn't realize he was being boiled alive until it was just too late. Lipedema is like that - it sometimes starts out slow and looks like regular fat. Due to a lack of awareness from the medical community, those afflicted often go undiagnosed for years, if not decades. Despite the patient knowing something is wrong, symptoms are often written off as common obesity. We have a lot to gain by educating the people around us about lipedema.

This lack of awareness frequently results in incorrect diagnosis and no diagnosis at all. This can lead to years of the patient believing the fatty areas were caused by laziness, bad diet, or poor lifestyle and are untreatable. The other result of incorrect diagnosis is that the untreated lipedema can progress to situations where sufferers become immobilized and ultimately, hopeless.

After more than a year of very active social media participation in lipedema groups, I've seen so many heartbreaking stories and pictures. Women, almost daily, go online and tell stories of how they went to their doctor or specialist, armed with information about lipedema, hoping to find that partner medical provider who will aid in finding the correct help or giving just that next referral. Some are lucky enough to have a care provider like mine, who wasn't aware of the disease but took what I said seriously and was willing to read the information I'd provided. I was lucky to have a doctor who was curious as I went through treatment and made referrals when I asked.

But time and time again, this is not the story. I've heard of women being fat shamed, scolded, and told lipedema is a made up condition. Many patients are humiliated to the point of never wanting to seek any kind of medical care again, including receiving preventative tests like mammograms, because they cannot face another round of humiliation and lecture. Even though their stories and symptoms are real, without proper medical support they end up in situations where the disease is untreated, progressing with the diseased painful fat continuing to build up, even blocking the lymphatic system in the body. And this begins a cycle of swelling, fat folds, and the development of infection. Blocking the lymphatics with extra weight can lead to development of lymphedema, open wounds, fibrosis and hardened skin. Some women lose their mobility permanently.

A sad part about this is that while lipedema is now actively, heavily being researched, what we know is that a good deal of management of the condition can be done by oneself. Today we

have access to sites like Amazon, where we can find inexpensive compression in many levels to try, Velcro reduction wraps, and (the few that exist) books about the disease. We have YouTube, offering numerous videos on lymphatic yoga, manual lymphatic drainage, and so many people's personal lipedema journeys that offer encouragement and hope. But if a woman never hears the word lipedema or is shushed when discussing her symptoms, she may not even pursue the freely available treatments she could be doing to prevent progression, and that's not fair.

One of the many reasons that there can be misdiagnosis is a simple lack of education about lymphatics by medical professionals. According to an article by Stanley G. Rockson et al, called *Lymphatic biology and disease: is it being taught? Who is listening*, "the average American medical school graduate receives an exposure to the lymphatic curriculum for less than 30 minutes within a four-year medical education." This puts medical providers in the precarious situation of literally not being able to make the correct diagnosis or referrals to patients whose situations are truly time sensitive to avoid progression.

Another major reason that misdiagnosis happens is because doctors, like the regular public, do indeed have fat bias. A study conducted by assistant professor Sarah Nutter at the University of Victoria showed that 18 percent of physicians surveyed agreed with the statement, "I am disgusted treating patients with obesity." The result of this bias can be catastrophic when it comes to getting a correct diagnosis for a condition that often looks like obesity.

If you find yourself with a doctor who blames all of your symptoms and conditions on your behaviour or who won't even give you the time to look at a pamphlet or information on any disease you suspect you have, I highly urge you to ask this question: "Is this how you would diagnose someone of average weight showing similar symptoms?" If the answer is no, get up and walk out. You know your body more than anyone else. If you have a gut feeling that the doctor isn't giving you the correct thought and care, seek other medical care until the fit is right.

## A Special Note to Medical Professionals

You may have a patient in front of you today who has symptoms of obesity and who is asking you for your help in finding the correct treatment. They may have a pamphlet for you with images of women who have a disease called lipedema.

You may notice that your patient has unusually large legs, hips and buttocks or arms, and they may be out of proportion to other areas of the body. You may notice palpable nodules (but not always) in these areas as well. Her blood work may appear normal, and x-rays and MRIs will not reveal the disease she may have called lipedema.

Please take five extra minutes with this patient today. She's most likely ashamed of her looks, feels pain daily, and has wondered what is wrong with her legs for years. She's probably been fat shamed in the public, told to lose weight by many, including medical professionals since puberty, and feels 'less than' other women. She's probably experienced trauma repeatedly in her life due to her weight issues and she's coming today to you, a trusted provider, for help.

All she needs is for you to listen, and compare what she's saying to what is in the clinical diagnosis information for lipedema. Please don't immediately discount what she's saying. She's coming to you for help today, and the care with which you treat her could change her life forever, to find validation first in her symptoms, and to find a way to much needed compression and other therapies and even surgical treatments to help remove the painful fat.

How you care for this patient may be the turning point in her ever seeking medical care again. If you choose to fat shame her, you would not be following your Hippocratic Oath to do no harm. For fat shaming and embarrassing this woman, may stop her from seeking the treatment she desperately needs, and prevent her from trusting medicine again.

Please just take the time and care this special patient needs, the same treatment you would want for your daughter if she came to another doctor seeking help.

There is a new standard of care for lipedema published now. If you're not familiar with it, know it was created with a consensus of many researchers who've dedicated their lives to adipose disorders. By learning to help this one patient, you will be helping many in the future as well.

**Medical Professionals – this is the information your patients need to be clinically diagnosed and to guide you in identifying next steps for treatment.**



**Standard of Care for Lipedema in the United States**

This is one of the many long term impacts of misdiagnosis.

*“Considering how much dieting and extreme restriction messes with hormone levels I really wonder what I’d look and feel like if I’d never been forced into a cycle of disordered eating and over exercise as a child. It stuck with me through my life and did irreparable harm.”*

*~ Member of online lipedema community*

# Chapter 5: A Correct Diagnosis

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## Lipedema Patient Story – Kasi



*"The year I turned 40 was the year my body finally made sense to me. In 2021, I was diagnosed with lipedema after spending nearly 25 years chasing down every diet, exercise plan, pill, supplement, and everything in between with no success. I come from a family of women whose bodies look just like mine- small on the top, but ever-growing hips, butt, and legs. In fact, the legendary "Smith Butt" is the stuff of many jokes over my lifetime but until I learned about lipedema, I didn't understand why!"*

*I had my first realization that my legs were different as a teenager, playing volleyball; finding knee pads that would fit my legs was so difficult, and even though I probably weighed about 120 pounds, even the largest size of kneepads dug painfully into my legs and left me with marks and swelling above and below the elastic for hours after wearing them.*

*As the years went by, my weight continued to creep up despite eating a healthy diet, maintaining an active lifestyle, and not drinking sodas or similar habits. After two pregnancies and during nursing, I managed to lose close to 80 pounds on Weight Watchers and my lower body/pants barely went down by only one size even with that amount of loss.*

*Over the years, I have noticed increasing symptoms including heaviness in my legs, strange skin texture and coloration, traumatic bruising and scarring, numbness, tingling, and abnormally cold feelings in my arms and legs, failure to lose weight in specific areas despite significant weight loss in others, and inability to cross my legs comfortably. I've been to many specialists, and no matter what symptoms I presented with, it always came back to comments about how I just needed to lose weight; which is especially infuriating when I knew I was "following all of the rules"!*

*I have spent my life feeling self-conscious about my appearance, judged, mistrusted, gas lighted, and often fat-shamed by the medical community. Some well-meaning doctors have insinuated that I have not been following medical advice, hinted that perhaps I must be snacking and binge eating and lying about what I said that I ate or forgetting to track it, not exercising enough, and just not doing enough to properly control my weight. The burden of hearing these messages repeated for 25 years does a number to you, mentally!*

*Finally, I found out about lipedema from a family member who attended a medical conference where The Lipedema Foundation had an informational booth. Her research on lipedema led her to our local hospital's Lymphedema clinic, and they graciously took me on as a patient and changed my life with the lipedema diagnosis. With the addition of comprehensive conservative treatments, support from an amazing lipedema community, and the resources to advocate for myself, I am now surrounded by a competent care team of multiple physicians who believe me, support me, and are helping me learn to thrive with lipedema."*

## **What do I do if I Think I have Lipedema? Who can Diagnose it?**

While any doctor can technically diagnose lipedema, few have adequate training in how to do so. This lack of education leads to delays in diagnoses, or symptoms being written off as traditional obesity.

If you believe you have lipedema, I recommend starting with your primary care provider and bringing a copy of the Standard of care for Lipedema in the United State (cited in the bibliography) with you. I recommend bringing a printed copy, as doctors are busy and may or may not have time to look items up for you.

If your doctor is unwilling (for whatever reason) to give you a diagnosis, you can ask for a referral to a lymphatic specialist, an occupational therapist, or to a lymphatic clinic. Or, you can do what I did and find a true lipedema specialist using the provider directory and call them directly. I'm lucky that my insurance company doesn't require referrals, allowing me to make my own appointment and start the treatment process.

The Lipedema Project has put so much work into assembling a directory of all types of lipedema providers, worldwide, that I'd be remiss not to share it with you in the book. I refer people to this site daily.



<https://lipedemaproject.org/lipedema-lipoedema-lipodem-provider-directory/>

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## Who is the Right Doctor for Me?

Everyone deserves a clinician that treats their patients like a trusted partner in the treatment of his or her own body. Doctors should be willing to listen to you, consider your suggestions, and believe you when you tell them how much you eat, how often you exercise, and any symptoms or pain you're experiencing. If your doctor doesn't listen, is authoritarian without considering your input, or fat shames you, consider getting a new doctor. You know when the fit is right.

For treatment of lipedema, please consider going to see a specialist who has been trained and knows the standard of care so they aren't trying untested methods, medicines that aren't known to be effective or related, or that try to give you things like diuretics, which can be counterproductive for patients with lipedema.

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## How do They Test for Lipedema?

Sadly, there is no blood test, x-ray or MRI that can be used to verify lipedema. The diagnosis is made by clinical exam only.

According to the *Standard of care for lipedema in the United States*, there are multiple criteria to guide the diagnosis that include history/family history, a physical exam, signs, and comorbid conditions. This list isn't conclusive but it includes things like when the condition started, how hard it is to lose the fat, enlargement of legs, easy bruising, palpable nodules, painful tissue, limb swelling, hypermobile joints, loss of elasticity, lymphedema, and vascular disease.

Because the *Standard of Care for Lipedema in the United States* is relatively new, and it was written by no less than twenty one doctors and researchers, it is extremely important that this document get in the hands of the professionals treating you, including your insurance company. This sole document may be the source of your winning appeals and getting those referrals for treatment, so print it out, bring a copy with you to all medical appointments, and provide a copy to your insurance provider if any of your treatments are questioned or disapproved.



The Standard of Care for Lipedema in the United States.  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8652358/>



Wearing shoes I bought on Amazon, and Bioflect compression leggings that I bought on Amazon – not custom fit. I had to self-procure these items knowing I will actually wear items that are easier to get on and look a little bit more mainstream. But I had to do the research, make the purchase, and decide to wear them. There was no one telling me what to buy that would work for me. I also had to completely figure out a new work wardrobe style that fits my lipedema-accepting lifestyle.

## Chapter 6: The Bad News? You Literally Have to Take Charge

A common thread that I see with members of the lipedema community online is that we are all looking for information to figure out our disease, the treatments, where to go, and so forth. There are a couple of companies out there that will attempt to guide you to receiving insurance approvals, but there, so far that I know of, isn't a company that will take you from soup to nuts in the journey of lipedema.

Personally, I had to basically demand that my doctor give me tests, even repeatedly, and then when I heard the word lymphedema, went back, and asked for referral to a therapist. I then had to get help and support by looking to social media, as I didn't know what resources were available in Oklahoma as far as support or trained providers. Sadly there wasn't anyone here for me to reach out to.

My therapist is trained in lymphedema and is certified in water therapy. Fortunately the techniques she uses also apply to lipedema, but she has had to learn a lot along the way. Now I refer other lipedema patients to her when they're getting started and in my area. Sometimes we see each other in the waiting room! I had to take the initiative to call Dr. Schwartz, go back and forth to pre-op appointments in my home town, get the covid tests, the blood work, schedule the pre-op cardiac testing, all individually, and without help.

I did the research on aftercare and scheduled that. All of the providers at the time I was going through surgery, were not connected to each other, and there was no streamlined process or checklist to go through. There was very little information out there on what post-surgical recovery was 'really' like (they tell you you'll leak, but really you do not know until you live it, believe me!).

Even over the course of the last year, research on lipedema has grown exponentially. There are more and more sites popping up, led by patients and advocates, to share and collate information, more sharing on social media, and more awareness with doctors - even more books! And we need every one of these things and more to continue to raise awareness, as long as women are going untreated.

If you're new to the lipedema journey, be persistent and insistent and consistent in demanding your treatment and asking for help. Hopefully someone out there is making a full-service company supporting patients from the time they think they have lipedema, to testing, pre-op testing, and providing compression, post-surgical care and lifetime treatment. But we're not totally there yet. It'd be even better if the companies were spread across the globe instead of patients having to travel long distances to find that one specialist who will help.

For now, we are grateful to the doctors and researchers, therapists and nurses who have dedicated their lives to women with a disease that is offensive to some in medicine. We thank you and hope you will continue to help us.

# Chapter 7: Dealing with the Psychology of Having Lipedema

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## Lipedema Patient Story – Debra



*“How has lipedema affected me psychologically? It’s a companion that I’ve had a relationship with for longer than some of my family members. No doubt that lipedema is like most chronic diseases, it has a way of shaping a person at their very core.*

*On the positive side, it has given more strength than anyone else out there might know. People with lipedema have to “sloth” through life. The simplest*

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*tasks are done in what feels like cement. There is a lot of pain and struggling.*

*On the negative side it has given me self-doubt. Being told all the time by most of the people in your life that you could do better or be better or look better if you just worked harder. I've reached a time in my life where I've been living with it for so long that I've landed in a "I careth not" mode. No doubt most folks out there would interpret this as being crass. I have become my own woman, instead of letting lipedema be a monkey on my back. Lipedema will always walk beside me, but I don't accept it as a friend or even feel I must love it to love myself. I want people to accept me. My body is big but that isn't "ME."*

*I went through some rough years not knowing how to deal with it exactly. It's such a visual disease and in a day in age where the world expects you to look a certain way or not be accepted, it was hard. I'm to a point in my life where if people can't accept me for me then I don't need them. Lipedema makes my daily life hard enough without devoting energy to worrying about an individual's thoughts of me.*

*Lipedema causes some anxiety for me as well. Whenever you go out of the house that you have built to the comfort of yourself, must ride in a car that you haven't ridden in before or even travel on a plane, people with lipedema must think about, "Will there be a place for me to sit? Will I be able to walk to that destination? Will that hold me? How early do I need to start getting ready so that I can rest a bit before I must take off again and still be on time? Will there be a place to put my legs up at the end of the day for a while so that they don't explode?" These are the things that a person with lipedema must think about.*

*Lipedema is a dangerous disease because it sneaks up on you. It introduces itself as a friend. It wreaks havoc on a person's life yet the person is the one that is to blame, not the effects of lipedema. This unknown disease, to most, needs to be a curtain pulled back so that it can get introduced to the world and the fight for a cure can be focused where it needs to be: LIPEDEMA!"*

Having a progressive condition like Lipedema can take a toll on a person, who may have been gradually adding symptoms and suffering over the years. Maybe she was not being believed by doctors, friends, and co-workers. Maybe she was fat shamed or humiliated. Psychologically, lipedema patients can find themselves depressed, hopeless, and sometimes even suicidal.

A presentation given at the Fat Disorders Research Society in 2016 by Dr. Joseph Stutz revealed research showing that 8% of lipedema patients had attempted suicide at least once, compared to 2.2% of unaffected females attempting suicide. This rate is very alarming and shows that the disease can lead to feelings of hopelessness without a plan of treatment. Education and advocacy are doing more than saving people's quality of life. In some cases, it is literally saving people's lives.

Additionally, undiagnosed lipedema can lead to eating disorders. The same research as above shared that as much of 75% of lipedema patients have suffered from an eating disorder.

As you can see, there are all kinds of emotions that we as lipedema patients may go through. Other feelings we experience can be:

- Shame and embarrassment
- A sense of betrayal by your body
- Not being feminine
- Feeling undesirable
- Feeling like a failure
- Feeling like you are different from other people
- Feeling a fear of loss of mobility
- Depression
- Feeling isolated and alone in the fight
- Feeling not supported or believed
- Helplessness
- Anger
- Anxiety about social situations
- Fear and anxiety about experiencing pain
- Medical dislike and fear of surgery or treatment
- Fear of others seeing your body
- Loss of control
- Fear of intimacy
- And in general, feeling post-traumatic stress from years of these things and numerous individual traumatic events

If you have felt or feel these emotions, your feelings are valid. No one has been through what you have exactly like you have, and you do have the right to feel them.

It's important to find the right support to help you get through your treatments and the rest of your life. There's a lot of mental baggage associated with this disease to unpack, and tending to it can help you move forward psychologically.

There are multiple people to whom you can reach out. If you are suffering from depression or suicidal thoughts because of your condition, reach out to your doctor to discuss available medicines. There is absolutely no shame in getting help of this nature. It can be life changing.

Finding a support group is a great way to reassure yourself that you are not the only person suffering from this affliction. Support groups, both in person and online chat groups (including Facebook groups), are a great place to find comradery. Look for lipedema patient roundtables (often advertised on Facebook), webinars from doctors, and in-person support groups. Finding others with similar symptoms and stories can be comforting and a source of care when you may be grieving the life you thought you were going to have.

Counselling can also be extremely beneficial. For those either unable or unwilling to go in person, online counselling services like BetterHelp.com are available at a low cost that can be done from your home.

Lastly, taking time to say or write your feelings down daily can also be a quick activity to get you through and help recognize what's going on. My therapist asked me to write down times when I feel like a fake or not enough to be where I am, and to get those thoughts out of my head and onto the paper. She gave me exercises that involve writing what I bring to the table and asking myself, "What else has to be on this list for me to fit in?" The answer has always been, "nothing." I have a right to be here, too.

This is an area that can lead to acceptance and joy, and it takes a lot of time to dig into. Always remember that your feelings are valid, there are resources available to you, and most importantly, that you are not alone. You are like many other women, and you have experienced many things that other women worldwide have experienced. You have a place on this earth and a reason for being who you are. Enjoy life and be proud of the only thing that is with you every second of your existence here – your body.

## Chapter 8: Treatment Options

The goal of lipedema treatment is to help us to live a normal life. That means managing pain, staying mobile, reducing inflammation, keeping the lymphatic flow going, and making sure you are mentally, emotionally and spiritually cared for.

I have an upcoming chapter about not letting your guard down, and I'm going to repeat some items from there here. There are literally so many things you can do right now to help manage your lipedema. Number one, sadly, is to reduce your sugar intake.

Number two? Get yourself some compression. Unless you have a medical reason (talk with your doctor for sure), you can buy compression online and start wearing it tomorrow to help keep your inflammation and swelling at bay. Later on, you can get fitted for custom compression if you need it, but compression key to reducing swelling, and the less swelling we have sitting on our bodies, the less it will turn our tissues into fibrosis. Compression helps prevent progression of lipedema. There are groups on Facebook that trade and sell used compression, as many of us try brands that don't work but want to share compression at a good price – it's worth a look!

Discuss treatment options with your trusted provider. Will you only do at home management like diet, compression, manual lymphatic drainage, and dry brushing? Will you try using a vibration plate to help move lymphatic fluids through your body, or a compression pump to help move the fluid out regularly? Will you try some of the supplements that women take and that are recommended by leading researchers, such as serrapeptase or Mucinex? (Please talk to your doctor, for real). Or has your condition advanced to the point where you are losing mobility and need to seek surgery from a specialist?

A consideration of the treatment you receive, sadly, is based on what you can afford. Whether it be with the support of an insurance company willing to pay or a self-pay type situation, surgery takes an investment of both time and money. Keep in mind that surgery is not a cure, and you will need to continue wearing compression, moving, and eating well for life in order for it to keep your whole body in the best condition you can, for as long as you can. Even with surgery, your body will most likely not look like the models on the front page of the latest magazine. Be sure and set a realistic goal for pain relief, mobility, etc. and please don't base your treatment expectations solely on looks, because you will be disappointed.

When I received my diagnosis in my mid-forties, my mobility was already starting to be affected. My legs felt so heavy and my knees were dislocating several times a day from the fat pads pushing against them, and I had to take dramatic action with surgery as my best option.

Also consider when looking at your treatment plan, your age and health status. I've mentioned before that my mother has lipedema and is nearly immobile now. Unfortunately due to other medical conditions including heart disease, she is not a candidate for surgery. If you find you are not a candidate for surgery, don't give up on the other conservative treatments as they can definitely improve your condition and provide relief.

I will get into my surgery stories later in the book as well, but I wanted to share with you my blog posts about getting accepted by Aetna and how I did it. I send links to these articles to new people in the lipedema community multiple times a week.

Finally back to diet. There is new research about the correlation of a keto diet and management of lipedema. I feel like this is an area I'm planning to personally investigate more as I age. It's a tough diet to follow and pretty dramatic for a food lover. I'm currently watching the results of several folks on the social media boards to make my own decision in this area. The Lipedema Project has been posting quite a bit of information on keto at the following link, and I watch this page regularly now. This may be an area you'd like to review!



From [www.legslikemine.com](http://www.legslikemine.com):

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## **LLM Blog Post: Answers to a Common Question: What Process Did I Use to Get Insurance Coverage for Lipedema?**

Posted **January 31, 2021**

Greetings and Salutations! We all know that lipedema is a real disease, and that the World Health Organization (finally) recognized the disease in 2018 with its own codes: (Code EF02.2 in the ICD11).

I originally wrote this post at 18 days away from my first surgery (of most likely, many) to get rid of the diseased tissue on my legs. I'm hoping that Dr. Schwartz will update his surgical plan for me to start on the interior legs, and remove the fat pads around my knees first, as they are causing my gate to be strange and my knees are both dislocating a few times a day now, and it really, really hurts. Like a deep hurt to the bone. This has actually been a progression that's occurred since my consult for the original surgical plan.

I've mentioned before that I'm on as many chat boards as I can manage about lipedema and I'm seeing so many questions about insurance approval, so I thought I'd walk you through my story.

Last year was an incredible year of learning about my condition. As my work stress was just OFF THE CHARTS last year, the condition in my legs worsened very rapidly. It was only late in the year that my doctor and I discussed stress and its direct correlation to lipedema nodule growth. But this growth influenced me to get serious about taking charge of my health and mobility so I dug into research like a mad woman for a few months. I learned that, while improvements are being made globally for coverage of lipedema surgery, many insurance companies don't cover it or give such a hassle that they weed out many people who deserve the surgery because they couldn't persevere through the red tape to get it approved.

At the recommendation of many of my support group peers, I contacted an insurance advocate. She called me the same evening as I the day I'd reached out to her and she talked through the overall process and made a recommendation to pay a fee to her nonprofit for assistance in getting through the insurance coverage process. I held off for a bit and continued to research. I started with my insurance plan options.

My employer offers numerous plans and we can change plans once a year during what's called an Open Season. So I looked at my current company (BCBS) and reviews from peer support group folks. I discovered that many Lippy Ladies had not been approved, some were approved after appeal, and some were caught up in red tape with this company. So I looked at other plans. I eventually came across an Aetna plan, and chatted with their company to find out they do provide coverage if the company deems it to be medically necessary. I also learned that companies publish their criteria and you can ask to see it.

So I discovered that Aetna has a medical bulletin for lipedema **here**:

[http://www.aetna.com/cpb/medical/data/200\\_299/0211.html](http://www.aetna.com/cpb/medical/data/200_299/0211.html). I learned that I meet all of the criteria and decided to change my insurance company for 2021, and made that happen.

While I was waiting for insurance to change, I gathered information. I grabbed receipts from my occupational therapist, amazon receipts for compression, bills from Tactile Medical for my leg pump, and Explanations of Benefits for physical therapist visits, OT visits, MRI trips, X-ray's. I went to my primary doctor's website and grabbed visit notes, test results from the MRIs, etc. so I had it all ready to go. I had two consults with my surgeon, and had received a letter of medical necessity, surgical plan, quotes, and medical notes so I already had that ready to go before January.

Once insurance switched out in January, I emailed the advocate again and consulted with them. Because I'd picked a high deductible plan, my goal was to get all needed surgeries done in 2021 to avoid multiple years of paying the big medical expenses. At that time I decided I would sign up with the advocate to get guidance and try to get approval on day 1. I will say, the advocate provides a trademarked process that has several steps that they have learned are helpful. I cannot share the exact steps with you, but let's just say that they've been through getting a lot of ladies approved and know what works. They provide guidance, in detail, on how to put your own package together to submit to the insurance company. It's not magic, but it's a lot. I came in prepared with all the items I'd gathered prior to seeing the checklist, and combined it with the recommendations from advocate to gain success.

The other thing I will say is that the advocate I used doesn't do the work for you. They don't have your paperwork and receipts and medical information so you really are responsible for putting the package together and getting it to the insurance company. They do provide guidance on the way and a review as you send to make sure you have the best package possible with the best likelihood of approval.

I'm sure that I'm one of the advocate's customers that make them lose sleep at night. I'm a government worker and delight myself in paperwork and rules. I did skip one of their recommendations for getting what i called a Functional Capacity Assessment, because Aetna didn't require it in their medical bulletin. It Aetna had it on their checklist I would have. It's around \$500 out of pocket to do that and I really didn't want to 1) spend the money or 2) take extra time to have it done. I took a risk in not doing it, and recommend you really talk with your insurance company before deciding not to do it The other thing is that I went through the process checklist on my own a couple of times, called the insurance company and hit submit and THEN i sent everything to the advocate. I'm guessing the nice lady at the advocacy company had a heart attack when she saw that (sorry!). Again – a risk, but I'm overconfident and under-patient.

So I want to add that you really have to read the fine print with your insurance company, call them first. I discovered that they have two forms I needed to complete and that even though the forms are ready, you have to call to start the process, the two forms are 1) the request for the surgery to be covered – they require precertification. And 2) a request to use an out of network provider (note this goes to a different location than the other package – tricky, Aetna (they emailed me this form)).

THEN submit the forms – I’m guessing this is a common thing that hangs people up. I got the forms in advance of calling, sent the ones needing doctor signature to my doctor and had them back, gathered up my stuff, took a deep breath, and called.

On the insurance call, I needed to have the letter of medical necessity on hand. They asked me for insurance diagnosis codes, treatment codes, the ID number of the surgeon and the id number of the surgery center. So be ready with this information so you’re not bumbling around.

After about thirty minutes, the insurance lady came back with an id number to reference and information on how to submit my forms. I was able to use an online fax service and just submit everything right then via electronic fax. I want to add that my advocate recommends using a cover letter on top of the package. They have a template (that I cannot share) that was very helpful in gaining precertification for the surgery itself.

I then logged into the Aetna portal and messaged them, asking for verification that my fax had come through. It had. I included both of the forms in my big package, and then saw that the out of network form had to be sent somewhere else. I loved the advocate’s idea about the cover letter so much that I decided to write my own cover letter to ask for the out of network coverage. I hear a lot of Aetna patients get approval for surgery but are told they have to use an in network doctor who isn’t a lipedema specialist.

So what I did is I wrote my own story, and I grabbed a lot of information from Dr. Schwartz's webpage blog that talks about why you want a lipedema specialist instead of a random surgeon. I've shared my letter on this sit, but I can also share it with you because it's not a template they provided me with - I wrote this one. Here is a link to the letter! I do have to redact a paragraph from the advocate but everything else is mine.

So I sent the other form and letter in using the Aetna portal, and got confirmation it was there and being reviewed. A week later, I got a portal notice telling me all my surgeries had been approved and the out of network request was also approved. I then contacted my surgeon's office and the advocate to let them know. My surgeon's office, who now has hired a full time insurance coordinator (Kelly), contacted Aetna to work on a single case agreement, meaning they negotiated on the price and contracted it together and I don't have to pay upfront and get reimbursed. THIS IS A HUGE WIN.

About three weeks after this, the surgeon called and said the agreement was done and I can schedule surgery. I still have to pay coinsurance/deductible up front (\$2900) but then I should be covered for the rest of the year on all medical stuff.

I want to give a huge shout out to the insurance advocacy world for walking me through and giving me confidence to try the approvals (totally shameless, unpaid plug). Also to Kelly and Daisy at Dr. Schwartz's office for seeing the process through. And to my mother for giving me the persistent Irish attitude to push through a challenging process on my own, I feel like this team saved my mobility, and also saved \$75,000. I'll share more as I progress to surgery. I hope this helps someone else wondering what the heck to do to stop this ridiculous and unfair disease from taking over. Much love.

Feel free to copy, use, or plagiarize the information in my letter. It's what I sent to Aetna.



**<https://legslikemine.com/2021/01/31/sharing-my-cover-letter-to-aetna-asking-for-out-of-network-coverage-its-all-true/>**

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## **LLM Blog Post: Sharing: My Cover Letter to Aetna Asking for Out of Network Coverage – It's All True!**

Posted **January 31, 2021**

In an earlier post, I walked you through the process I used to get insurance precertification and out of network approval in one week flat. This is the cover letter I wrote that went with my request for out of network coverage and a single case agreement. I think it's a great letter, and I borrowed a lot of information from Dr. Schwartz's blog to make it. Note I redacted two paragraphs that came from the an insurance advocate's process that they own, as it is part of a template for a different cover letter that they recommend be included in the original precertification package (different letter). Additionally, not everyone agrees with all the info I used to create this letter, but this is what I sent, and it worked for me, in my situation. Enjoy!



**Aetna**

**Aetna Address Redacted**

**Aetna Fax Redacted**

**RE: Name, DOB – non participating provider request**

**Member ID: Redacted**

**January 13, 2021**

**To Whom It May Concern:**

**On January 8, 2021 I submitted my precertification package requesting approval for surgeries to treat my diagnosed disease of lipedema. I have not yet heard the outcome of the precertification request.**

**Additionally, I requested a single case agreement with my surgeon Jaime Schwartz, MD, who is out-of-network as an in-network provider, and that he be paid as an in-network provider, by submitting the Nonparticipating Provider Request form with my precertification package.**

**In submitting this request for non-participating provider specialist on my "Precertification/Preauthorization Nonparticipating Provider Request," Form GR-67353-12. I find there is not enough room on the form to justify the use of this specific specialist in lieu of a general surgeon, or general cosmetic surgeon or other possibly in-network surgeons. I am requesting that this information be added to my package as justification for using Dr. Schwartz, a lipedema specialist:**

**Jaime Schwartz is welcoming to accept high risk cases like mine, where my Body Mass Index is high and I have a history of a blood clot. The other surgeon I consulted with (Dr. Redacted) required me to lose weight, which is not possible having lipedema and not metabolic fat. Schwartz has specialized equipment and has several different types of equipment at his disposal.**

TWO PARAGRAPHS FROM AN INSURANCE ADVOCATE'S COVER LETTER TEMPLATE HAVE BEEN REDACTED.

**Jaime Schwartz is a board-certified plastic surgeon and renowned lipedema specialist. Founder of Total Lipedema Care in Beverly Hills, CA, Dr. Schwartz has dedicated part of his private practice to helping women hindered by this disease. Dr. Schwartz continues to research and figure out answers to this complex disease that seems to be driven by a woman's hormones. Lipedema specialists, like Dr. Schwartz, are finding ways to reach these women in the early stages so they can have the emotional and physical support as well as treatment options to live with this disease.**

**Lipedema specialist Dr. Jaime Schwartz is dedicated to taking a further look into this condition and how he can help women suffering from this potentially-debilitating disease. Schwartz can help patients with an early diagnosis which is essential to getting the early intervention help and emotional support that lipedema patients need.**

**Places like Total Lipedema Care are centered on giving women surgical options, treatment plans, and additional avenues for support in order to have a better quality of life while living with this disease.**

**Most women who have lipedema are embarrassed about how they look. Lipedema causes a woman's lower half, particularly the legs, calves, and hips to be over-sized while the upper torso remains the same. One of the main reasons lipedema often goes undiagnosed is because it is commonly mistaken as a weight issue by other medical professionals. It is a physically and mentally challenging disorder and most women go through it alone.**

Finding a lipedema specialist, like Dr. Schwartz, is imperative to the support that every woman needs on how to deal with this disease and keep it from progressing. Lipedema patients need to feel comfortable with their specialist in order to convey what they are dealing with and discuss any issues. A definitive diagnosis allows a lipedema specialist like Dr. Schwartz to have a better knowledge and understanding of what each patient is experiencing in order to devise a treatment plan.

With his extensive knowledge of this disease, Dr. Schwartz can help rule out any other conditions and give an accurate diagnosis. This can allow for the right treatment options to begin promptly. Dr. Schwartz is extremely skilled in all aspects of lipedema, from its earliest stages to the more severe, advanced stages. This knowledge allows him to monitor and help his patients every step of the way. Dr. Schwartz and the professional staff at Total Lipedema Care can give nutritional guidance, recommend physical therapy or water exercise programs, surgical and nonsurgical treatments, and even psychological counseling.

Schwartz is not only a lipedema specialist but also a board-certified plastic surgeon. Because of this, he can provide treatments that offer relief from certain lipedema symptoms. Once such treatment is water-assisted liposuction (WAL). This procedure essentially decreases the congestion and inflammation in the legs where lipedema is most prevalent. Similar to, but not, a cosmetic liposuction, fat in the targeted treatment areas will be removed. Dr. Schwartz also employs the SAFE liposuction technique – separation, aspiration, and fat equalization – to get as much fat out as possible while not putting the shape of the area in jeopardy.

Another surgical treatment option for lipedema may include excess skin removal for areas that have lost elasticity. This skin can actually hinder lipedema patients, especially if it gets infected, impairs the mobility of the patient, or prevents compression garments from fitting properly.

Since there is no cure for this hereditary disease, working closely with a lipedema specialist like Dr. Jaime Schwartz will help improve symptoms, provide ongoing care, reduce leg size or complications with surgical help, and provide emotional support. Living with this disease is a daily challenge but having a relationship with a lipedema specialist like Dr. Schwartz is beneficial in so many ways.

Thank you for your prompt consideration of this matter.

Susan A. O'Hara

If you took the time to read through my blog posts and letter, there are some key takeaways from them:

- Take notes and keep all the receipts as you prepare your package
- Keep a running sheet of every expense, including mileage to and from appointments, related to lipedema
- Ask questions
- Take pictures, and ask your doctor for access to their pictures, notes, and test results throughout your journey
- Keep a log of what you're doing and when
- Save all your information in one place so you can have a good package when the time comes.
- Be assertive and kind and if you get told no, ask again, ask the supervisor, and appeal

Because the route I took for treatment heavily involved surgery, a large portion of my book is dedicated to the surgical experience. The next section comes from my blogs where I documented my experience.

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## **LLM Blog Post: Round 1 of Surgery to Remove Lipedema is Drawing Near – I'm So Ready, and a List of Things I Plan to Bring!**

Posted February 9, 2021

I thought I'd provide you all an update on where I am with having surgery. Dr. Schwartz's office called a couple of weeks ago on a Friday evening to let me know that my single case agreement with Aetna had been approved. All I would need to pay for all the surgeries would be the \$2900 deductible and everything else would be covered. This is a huge win, especially since all of this occurred with one submission of paperwork. The surgeon had a cancellation for February 17th and I took it.

The minute you get a surgery date, there are many plans to be made quickly: travel arrangements, care arrangements, pre-op clearances, lists of things to bring, and doctors' appointments. My husband and I learned early on that the covid restrictions were a little bit hefty for a double trip to CA, to just sit in a room and for him to not be able to go in to any pre, or post-op appointments, or be there on surgery day.

We opted to use Pearl Recovery Retreat and have them pick me up from surgery and provide nursing care after surgery. Of course you know I'll provide a review after surgery. I immediately booked airlines, and other hotel arrangements using points and airline credits left over from before covid, when I used to be a very frequent traveler.

I had two or three phone calls with the surgeon's office to ask questions, and a form from work to fill out, which they worked on immediately. I got a big paperwork packet from the office as well that provided some expectations for care before and after surgery. I also got dates for pre-op, surgery time, and two post op appointments set. Dr. Schwartz's office also arranged for me to have a covid test before surgery with a doctor in the same building.

I consulted with several ladies in my support groups and got lists of things to bring and not bring, which I'm sharing with you below:

- Double Absorbency Bed Pads – this is for catching the massive amount of tumescent fluid mixed with blood that will leak for a few days.
- Dark Colored Top Sheet – for hotel
- Measuring Cup – for measuring output of drains. This gets recorded 2-3 times a day
- Shower Curtain – for hotel bed
- Tylenol – I seriously don't want to be on big pain meds long
- Poise overnight pads – dual use here including possibly having to tape them on my leg for the flight home if I'm still leaking. I know it's gross, but it's better than leaking everywhere.
- Cloth Tape – taping down pads
- Coban – this is the wrap stuff they put on your arm after a blood test, to hold down bandages
- Black Maxi Dress – to wear on plane home over whatever get up I have over the compression leggings I'll be wearing to hide who-knows-how-many-poise-pads I have taped to my legs. (grin)
- Hibiclens – soap to use 2x before surgery

- A New Razor – so I can pretend like I shave regularly in the winter, and all the places I don't normally shave.
- Baby Wipes – I think you don't shower for a week, so...
- Thermometer – for checking for signs of infection
- 2 dark colored towels – for who knows what emergency
- Dry Shampoo – I'm going to wash and braid my hair the morning of, but by day 4, it'll be time for a freshen up
- Q tips – for cleaning around incisions and drains
- Trash bags – for throwing all of this gross stuff away before I leave
- Benadryl – in case the compression makes me crazy itchy, or just so cranky that I need to be knocked out
- Inflatable elevation pillow – elevation is a must to keep swelling at bay after surgery
- Aquaphor – lotion to help healing once compression is off. This was recommended by the doctor
- Loose dark pants – in the off chance I can wear them
- Slippers – dark
- Dark colored sleep shirt
- Finally, printed surgery confirmations for travel
- 

Note a couple of folks have recommended some supplements that I want to talk to the doc about on pre-op. If he thinks I should have them, I'll grab them at a local Walgreens or CVS. These include electrolytes (powdered), an Arnica supplement, and a Bromelain supplement.

For me, I had to move some savings around and that took a couple of days, then I called the office and paid my \$2900. I still have some expenses, which I think I will save for a blog after surgery to kind of give you an idea of what it was like for me. Of course, everyone's expenses are different, but this will just capture one perspective.

Finally, I met with two doctors here to have cardiac clearance and an EKG, extensive labs, and a physical. I also needed a med change for blood pressure due to my classic White Coat Anxiety. Gotta love it. Tomorrow, I will verify that all these tests and clearances have made their way to the doctor's office and I'm all set.

A day or two before I leave, I will have some meds called in to my local pharmacy – I think an antibiotic, and a pain med, and then something to prevent Deep Vein Thrombosis post-surgery like a Lovoanox injection (seriously, no big deal), or Eloquis (?).

Once I get into town, I'll relax for an evening, then get up for an 8 am pre-op, then covid testing, then I have to go buy some protein shakes to drink after surgery (3x/day). I should get a couple of calls from the doctor's office after that to finalize times for the next day.

I think that catches up where we are for now. But have I mentioned that I'm super ready to get these legs fixed? I keep looking at before/after's and hearing how much other ladies like me have had their mobility restored and pain reduced from even one surgery, I cannot wait!!!

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## **LLM Blog Post: My Lipedema Surgery Story – The Days Before Until Paul McCartney Knocked Me Out**

Posted **March 3, 2021**

So I'd posted a bit ago sharing the things I was planning to pack and what I thought would happen before surgery. This is a continuation of that post.

A couple of days before surgery, I got an email letting me know that several prescriptions were ready for pickup at my pharmacy. Dr. Schwartz had called in everything he can across state lines, so an antibiotic, something for physical nerves in the legs, a stool softener, and ibuprofen. I grabbed those a couple of days before flight time and then watched the weather. Unfortunately, the big blizzard to cover the entire USA was coming and I'd probably miss my flight. I changed my flights a couple of times, leaving a full day earlier than planned and also to fly through Phoenix instead of Dallas, which did end up being hit hard with the blizzard.



My blizzardy drive to the airport.

I got up super early on Valentine's Day and drove in already blizzard conditions to get to the airport before things began shutting down. While I did have some delays and a missed flight, I got to California while the sun was up, checked into the hotel and had carry out for dinner.

For pre-surgery days, I stayed at The Residence Inn Marina Del Rey on Marriott points (I was a prolific traveler before COVID). This is a brand new hotel on the water – giant yachts are right outside the window, and the restaurant overlooks the water.

I was easily able to call an Uber or Lyft from this location and jet into LA or Beverly Hills. This hotel has suites with kitchenettes and such a nice atmosphere that I will stay there again. In the evenings I enjoyed walking by the water (very safe area), and then heading up to the rooftop bar area (closed bar) to enjoy the fire pit and the LA skyline. They also offer a free breakfast, which helps a little on an expensive LA trip.

On Monday, I had a free day since I'd travelled early. It was a holiday as well. I had the free breakfast, and then decided to not waste the day. California had just reopened outside only dining. I hopped in a Lyft and rode up to Santa Monica. I saw a Fantastic Sam's hair place, and since I hadn't had a haircut in now 14 months, I decided to treat myself. I had the lyft driver turn around and drop me off.

Sam's had the windows and doors open, and the weather was perfect. I really enjoyed chatting with the few folks in there while I got a cut and color. When I got done, I walked next door and grabbed a few groceries from the store, just enough to fit in my backpack. Originally I was going to go to the CVS pharmacy to pick up my protein drinks, but I decided instead to walk up and down the pier and beach, and I enjoyed dining at an actual restaurant for the first time in forever, outside at Blue Plate Taco. Food was amazing.

The sun felt amazing. I walked around until close to dark and then caught a Lyft back to the hotel as it feels like things could get a little sketchy at dark around there. Always a safe bet to be in by dark in an unknown city alone.

Tuesday was pre-op day! I had an 8 am appt. so I made myself a quick oatmeal breakfast in the room, caught a Lyft into Beverly Hills and was on time. I met with a nurse, who had me undress to the underwear and put on a bariatric sized gown (YES), took vitals and asked about my blood pressure. I noticed while we were in the exam room that the Beatles were playing, and this relaxed me (I've travelled FAR to see Paul McCartney a couple of times and am a huge fan).

We talked about whether I'd gotten my meds yet, if I had any questions, etc. for a while. I signed all of the paperwork for surgery on an iPad.

Dr. Schwartz came in and talked with me, then had his first in-person look at my legs. We decided that the back of the calves was the worst and most fibrotic area and that should be where my treatment starts.

I had several opportunities to ask questions and would also meet with him again the next day. They went over that the anesthesiologist would be calling me that evening and then I went in for pictures. I signed a photo release to photograph everything, share everything and give me copies of everything because I blog and I want to help other people.



I wore my LegsLikeMine shirt through LA that day –  
shameless plug!

Unfortunately, I have “white coat syndrome,” which makes me really anxious when I walk in the room and high blood pressure. I go called back into the room to do a BP check again. I had a med change two weeks prior and had been logging my bp – I shared my most recent numbers with the nurses as well, and that seemed to satisfy the doctor, who was getting updates bit by bit. Then I was released to do covid testing and pick up my opioid pain meds.

I was able to go downstairs to another doctor's office and grab a quick covid test – no issues there. Then I went to the Hepps pharmacy, which is also in the same building, to grab my script. I was planning on getting some hibeclens to wash with before surgery, but they were out. So I took a Lyft to another pharmacy where I grabbed the hibeclens and a canister of on-sale protein shake mix. Ready to go!

The rest of the evening, I rested in the hotel room, took Goodbye Pics of my legs, and packed up for the morning.



My mom and I have always called our legs, “deformed.” I took this picture of my calves the night before surgery. Goodbye deformed legs! And thank you for all of the wonderful places you have, and will take me.

The next morning, I met my arranged Lyft driver at the hotel. He drove me to the Viceroy Hotel which is, as my driver described, “very very luxury hotel.” The viceroy front desk was expecting me, and walked me to the elevator and pushed the button for me to go up to the Pearl Recovery Center to drop my bags. I then returned to the Lyft and headed to the surgery center in Dr. Schwartz’s office for my surgery.

At the surgery center, no time was wasted. They had me change into a gown, and gave me surgery panties that didn’t fit. I didn’t wear them and mentioned it. It’s like my only close-to-a-constructive-feedback I’d offer about Dr. Schwartz’s office.



The itsy-bitsy, teeny-weeny, blue and white surgery panty.

They took my blood pressure, which was fine, thankfully. They had me take I think gabapentin with a little water, pee in a cup for a pregnancy test, hooked me up to an IV line, and had me meet with the anesthesiologist. We went over meds and I filled out forms for the anesthesiologist. All the time, I chatted with the nurse, and Jerry who is the surgery assistant – they were both friendly and did a good job laughing at my nervous jokes.

Dr. Schwartz came in and examined me again. He got out a big marker and had me lay on the table and marked up his plan. He marked me all the way up to the diseased tissue on my hips and rear end, noting he would go as far as he could for patient safety. Then the best thing happened.

Dr. Schwartz handed me a red marker and told me to mark up what was hurting me and bugging me. I said, "This is Cathartic," while holding back tears. He told me that's why he does it. I asked him if I could write anything I wanted and he said, "Yep." So I circled Larry the Lump and I wrote, "F U Larry!" We all laughed so hard. Things moved quickly from here.



A final goodbye to Larry the Lump – sorry Mom!

Dr. Schwartz disappeared, the nurse and I took one more round of photos with the markups, and then I got back in the bed. The nurses asked if I liked any music in particular and I said Beatles. As they wheeled me in, someone yelled, “Hey Alexa, play the Beatles!”

The anesthesiologist placed a mask on my face and I started singing “Hey Jude” along with the song that came up. I said I’d seen Paul McCartney sing this live in Madison Square Garden. As I started to tell about seeing him in Illinois with Aunt Linda, I raised my hand to talk, and Paul McCartney said, “Don’t make it bad.” Then I was out.

Every time I think of this moment, I get teary eyed. Thanks, Paul for being there with me and knocking me out.

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## **LLM Blog Post: I’m Back from Surgery #1 and I have SO Much to Tell You!**

Posted **March 1, 2021**

Hi there, I’ve been home from California for a few days now. I’m still recuperating and am off of pain medications completely. The doctor removed 8 Liters of diseased tissue from my calves and I will need at least two more surgeries to get it all.

I’ve documented each day before and after surgery and will begin sharing some of these with a daily post that I write in the evenings. I’ve been actively updating several social media channels (numerous Facebook groups, primarily) over the last few weeks, and social media has gotten out of control! This is a good thing.



My leg, and Larry the Lump, right before surgery.

Right now, I'm getting more than 1000 messages a day from ladies wanting to know so many facets of my story and I'm answering directly, but also making an FAQ list of items I just need to blog about so I can answer it once and point to the link.

For now, let's say surgery was great - I felt great the first two days, and then slowed down with swelling and soreness. I rested - big time - and now feel pretty great on day 11 post op!

Thanks to you all for the care and support and be looking for my post tomorrow, which will outline the days before surgery and up to the moment they knocked me out.

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## Now this is Where it Starts Getting Fun! YouTube

On the way from surgery to my recovery center, I got this bright idea. I decided to start making videos of the whole recovery experience, posting on all the social media sites I'd set up, etc. I created a YouTube Channel and documented every part of the process I could think of. The first video is of a groggy, swollen me, talking about surgery just a few minutes after I arrived at the recovery center. The videos are things difficult to write and describe, so the content is very unique. I have to say too, not a whole lot of women have videos of themselves in anesthesia-ridden grogginess, showing leaking drains and dirty hair, but I wanted to share it all, and I did. I wanted people to know what to really expect after surgery, and I believe it's helped so many people.

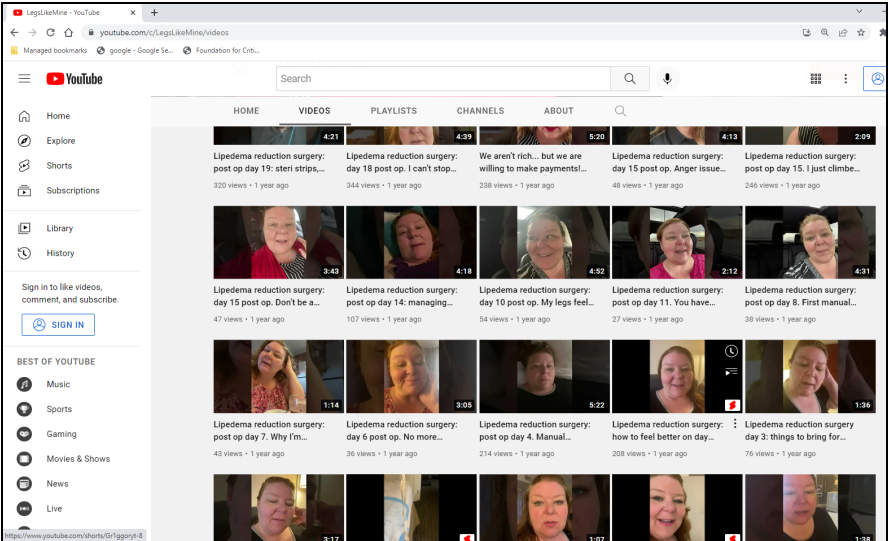
The very day I posted my first video, women began contacting me by the THOUSANDS each week to ask for more videos and for help. (I also had a few creepy-creepers with fat fetishes contact me, but I finally got rid of them for now.) If you're in for a binge watch and don't mind seeing a groggy eyed post-surgery Susan, feel free to go out and take a look at my channel. Most of what I do video blogs on, I do not cover in the written blog, Instagram, Twitter, Pinterest, etc. You just have to see the videos. I cover all kinds of topics on post recovery from the minute I got to the recovery center until the day I was released from occupational therapy after my third surgery. Other topics include:

- What it's like to stay at a recovery center
- My love-hate relationship with surgical drains
- Mood swings post-surgery
- Updates to the packing list for next time
- Manual lymphatic drainage during recovery
- First trips to the occupational therapist
- Starving for a week after surgery
- Looking at everyone else's legs now
- Anger
- Walking
- Compression hacks
- Swelling reduction tips: the dead cat shake / legs on the wall
- And more weirdness and fun

# The LegsLikeMine YouTube Channel



<https://www.youtube.com/c/LegsLikeMine/videos>





What my legs look like one year after the first of three lipedema removal surgeries. Not perfect, but so much better mobility and pain wise. And they look good enough for me to feel fine in shorts!

## Chapter 9: Fitting In

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### Lipedema Patient Story - Mina



*"Growing up I knew there was something different about my body. I began to gain weight during puberty which is normal for pre-teens. My weight went straight to my hips, thighs, and rear. My waist and breast were small which created a very exaggerated hourglass figure. My friends gained weight as well, however their weight was distributed all over their bodies.*

*People complimented me on having a small upper body and some even believed my body was created by exercising. I knew something was different about me when I began losing weight in high school and my thighs would not lose any inches. My hourglass figure looked extremely exaggerated which resulted in me getting a lot of unwanted attention. People began to obsess over my wide hips and small upper body. Some would give me compliments and some would make derogatory comments*

*that were offensive. It was very difficult buying clothes because my upper body was medium and my lower body was extra-large. When I had my first child in my late teens, I gained about 80 pounds. The majority of the weight went straight to my thighs. I could not lose any weight no matter how much I tried. I did water fasting, weight loss shakes, diet pills, low carb diets, even vegetarian diet plans that encouraged me to eat bread and rice. I still could not get into smaller sized pants and skirts. My self-esteem suffered because I felt uncomfortable and I had a hard time finding stylish clothing that would accommodate my huge thighs and wide backside. I began wearing long stretchy dresses and loose fitting sweats and slacks out of the men's department stores.*

*Doctors encouraged me to see a nutritionist, which I did. The nutritionist gave me advice that I already had heard a million times. Eat less, cut out the processed foods, and exercise. I did exactly that. I had done that before, but still didn't lose much weight or lose inches in my thighs and lower areas. After years of yoyo dieting I still saw no progress.*

*I eventually developed leg ulcers due to veins in my legs not working properly. I struggled with the painful leg ulcers on and off for about 5 years. The ulcers would heal, then they would come back which indicated my legs were not getting proper circulation. I was referred to a vein surgeon that told me about lymphedema and lipedema. They referred me to a massage therapist that specializes in patients like myself. It all made sense why my legs were larger at the bottom and why I had so much trouble losing weight. My body was holding on to fat as if it depended on it. I am still learning about this condition and still struggle with body image, weight loss, and what is the next step for me. I have considered gastric bypass surgery and liposuction that would attack the lipedema in my legs. The process is very complicated and very expensive.*

*Right now, I am wearing compression every day, cutting out carbs and sweet foods. I walk and exercise daily. I do not drink sweet drinks such as sodas and energy drinks because of the sugar and carbs. I feel much better even though I do not see much changes in my weight. I feel great and I know exactly what is wrong. I am not the problem, my eating habits are not the problems. Genetics and going through stages in life such as puberty, pregnancy and menopause are my problems because this is when my lipedema gets worse. For now, I will continue living and doing research on ways to improve my living conditions.*

*This is just the beginning for myself and many other women on this journey."*

*"I wish I'd known that it's not my fault, that BMI does NOT equal health or worth, and that appearing, "healthy" is not a social obligation. If I'd been raised with these values instead of, "fat = abhorrent," my lipo-lymphedema wouldn't have progressed anywhere near the point that it's at now..."*

*~ Member of online lipedema community*

# How Can I be Fashionable with Lipedema?

There are so many things you can do to downplay your legs and arms, and I have seen some truly beautiful women in amazing outfits that actually show their lipedema areas. Here are a few things I've learned that really help me with fashion confidence.



Bathing suits: For me, swimming is my favorite and nothing is going to keep me out of the water. A few years back, I was wearing board shorts over my regular one piece suits, which is fine. And then I discovered the aquatard. It's a one piece suit that has the top of a regular bathing suit but the legs go all the way almost to the knee. To me, it looks a lot like something a SCUBA diver might wear. I do hard-core water classes in my aquatard, which I've had for several

years now, and I don't have to deal with it floating up or rolling down. It's perfect for me and my crazy level of activity. My aquatard has been with me to cruises, Hawaii, Mexico, and so on. When I see myself in this suit, the last thing I'm thinking is that I don't look like a supermodel. What I'm thinking is how much fun I had wave jumping in Mexico! I wear it without a cover-up and I just go and enjoy it!

I love maxi dresses: These are dresses that go almost to the floor and guess what, everyone's wearing them! I have these in casual, beach styles all the way to more formal styles that I can pair with a jacket for work meetings. Another good thing about them is that they can be relatively inexpensive and very comfortable. It's very easy to slip on a pair of compression pants under a good maxi dress or skirt and be as comfortable as wearing pajamas all day.

Outfits that incorporate compression: With compression, I can get away with wearing shorter dresses because some tight compression makes my legs look more normal. So if I have on a pair of black compression tights, I'll go ahead and put on that knee length dress that I never would have attempted prior to learning about compression. Another way that I pair compression is to wear butt-covering tunics or flowing big tops with a pair of compression and any shoe. Make sure to cover your bum with your top though because some compression can be seen through.



Flowing pants and palazzos are your friend. There are so many cute styles out now that incorporate big flowy pants. If you're lucky to have that small waist, accentuate it with a fitting top and big flowy pants. How fun and stylish!

Tops in general: If you want to draw the eye away from the trouble spots, use tricks like V-neck tops, statement necklaces, bright colors and patterns in your tops or eye-catching scarves and earrings. The eye will go there, where you're literally telling it to go. I also wear boot cut jeans, regular stretch pants, and I like to wear long kimonos and sweaters to add as my third piece to cover up the areas I don't wish to highlight.

As you can see, we do fit in and there are so many options out there. Be creative and know you are beautiful. That shines through any outfit any day!

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## What about Shoes?

If your feet hurt, everything hurts. I have numerous blog posts with shoe recommendations that I've made over the last two years on [LegsLikeMine.com](http://LegsLikeMine.com). Switching to sensible shoes has made a tremendous difference in my mobility and the amount of time I can be up and about.

I struggled with foot pain for years; deep, agonizing foot pain. I spent many years wearing terrible shoes like cheap flip flops, flats with no support, and often going barefoot for hours on end, simply because I could not find shoes that fit, provided support, and looked feminine.

After learning about lipedema, I began buying shoes that adapted to my swelling. Good arch support also became an important consideration. I got rid of 95% of my high heels, reserving just a couple of pairs for very short special occasions. And every pair of cheap flip flops went right in the trash – those things are the first ingredient in a recipe for a bad foot day, which turns into a bad knee and hip day now.

Today I wear good quality brands like New Balance, Aravon, Drew, Munroe, and David Tate. I will not put my feet in cheap shoes anymore, because there is nothing worse than foot pain to ruin a good hike or trip through Rome. I strongly suggest you talk with your doctor about shoes if you're having problems with your feet. You can get a prescription for orthotic shoes or visit places like the Good

Feet Store for higher quality and custom footwear. Many online retailers like Zappos and Amazon now have filters where you can whittle down the selection to shoes with specific features (like arch support and being orthotic friendly, which translates to me, to 'room to swell.').

Wearing the proper shoe will make all the difference in the world. And I'm learning that cute shoes do exist in these brands, but you have to dig and search and stop people in the parking lot (yes, people stop me about my Mary Jane shoes pictured in this book. I should make a business card for them in fact.) Do yourself a favor by doing some research, then spending a few extra dollars on a pair of shoes that fit your feet.

Just for fun, here's a QR code to all of the blog posts I have on LLM about shoes:



<https://legslikemine.com/?s=shoes>

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## Am I Able to Travel with Lipedema?

People with lipedema are often worried about whether or not they can travel. Those who fly worry about being able to fit in a standard airline seat. Those who drive may have concerns about being seated for long periods of time and swelling too much. The great news is, there are many tricks and tips that can make traveling more comfortable.

In a normal year I take several cross-country road trips, at least one international trip, and tens of cross-country airline flights. I've figured out a good system, and am sharing a few pointers with you here.

I wear compression when my feet are down for any significant period of time and I always do when I fly. I currently use a brand of compression that is relatively easy to get on and is tight enough to work, but not so tight as to be uncomfortable. The brand I purchase is available through Amazon, and it's not a custom fit. In addition to compression I also put a Velcro reduction wrap on my lower left leg, where I also have lymphedema that swells up when I'm not careful. I also get these wraps from Amazon.



Whether I'm flying in a plane or riding in a car, I keep my shoes on for the whole trip, no matter how long it is. And I wear shoes that cover at a minimum, my toe box area and heel. Most of the time I wear sneakers that tie for the really long trips. I've seen some people remove their shoes on international flights and not be able to get them back on after landing due to normal swelling. So people with lipedema definitely don't want to do that. I wear good shoes with ample arch support that are great for walking in so I don't have to deal with the normal foot pain that comes from the rush and bustle on travel days.

I am also careful about not eating additional salt, alcohol or caffeine a couple of days before traveling, including my day of travel. In fact, when the flight attendants offer drinks, I usually will go with water-no ice. This helps avoid additional swelling, water retention, and dehydration.

Every day and especially when traveling I carry a quart-sized water bottle with me, and am sure to fill it up as soon as I pass through the TSA checkpoint. I always have water with me, in order to stay hydrated.

To avoid potentially embarrassing situations I carry my own set of seat belt extenders, made by FAA repair stations and bought on Amazon. (Note Southwest has its own unique triangular shaped buckle, but most other airlines use a traditional rectangular style.) No system is perfect, and occasionally I forget to bring my extenders with me, and sometimes the ones I bring simply won't fit. When that happens I just politely ask, "Hey can I get an extender from you when you have a chance, please?" to the flight attendant. We are considered people with disabilities and we have the right to fly and to be safe with a seatbelt. (Note, I always return the borrowed extender to the attendants as I exit the plane so they don't have to find it on their own or depend on the cleaning crew to return it.)

It's no secret that the seats in first class are more spacious and comfortable than those in coach. When I can haggle it, I try to upgrade my seat. If that is not possible, I watch seat maps on each airline's app like a hawk and move my seats around several times, doing everything in my power to sit next to an open seat. I always check seat maps for 'moveable armrest' on the seat I select, because those permanent, solid armrests are the cause of misery, pain, and more dreaded mystery travel bruises.

One travel secret I often take advantage of is the Southwest Airlines Persons of Size policy. The way it works is you book two seats. For me, it would be like this. Seat 1: Susan O'Hara, Seat 2:

Susan XS O'Hara. On travel day, check in at the counter and if the agent doesn't pick up on what you've done, tell the agent you have an extra seat. They will give you a preboard card, which you will use to board. You'll also get a second ticket to put on your extra seat that says, "Seat reserved."

When boarding, make eye contact with the flight attendant while finding your seat. It's good to smile and inform them you have an extra seat. I'm pretty bold and will even ask if they will help me protect it. Sometimes I even bring my own tape and attach the "seat reserved" sign on the headrest of the seat! If anyone tries to sit in the seat, I just point to the card, and it always works. Now the BEST part about SWAA's policy is that if the flight doesn't oversell, the company will refund the second seat you purchased! But you have to ask for it. Unless you hear Southwest trying to buy people out of their seats at the gate prior to take-off, you're probably in luck. Don't forget to email the airline your information after the flight and ask for the refund per their person of size policy.

After the flight, I leave my compression on for at least a couple of hours unless I'm getting in water. But oh, if you can get yourself in a pool or the ocean, do it. The compression that water provides is very good and presses against your entire body, not just the legs. Swim as much as you can as often as you can, even when you're not traveling.

If you're still having swelling problems, try going "Legs on the Wall." What I mean by this is, lay down on your bed and put your feet as high up as you can against the headboard for as long as you can. If you can, rub your legs while in this position and do a little lymphatic massage, or even very deep diaphragmatic breathing to help lymph flow. Five minutes of this would be amazing; longer, even more.

My next bit of advice is a personal decision and probably not what medical professionals would advise, but I prefer to not travel with my flexitouch pump for a few reasons. First, is that it's very expensive and I really don't want to risk it being broken with all the bumps that happen to things on travel, whether checked or carried. Yes, you can carry on an extra bag free if it's a medical device but, my whole pump setup is two legs and a hip portion, and it fills up a large underbed storage bin, so it would be a pain to carry on. Finally, there is no way I'm checking in something that expensive and breakable. If it were to get lost or broken during a flight, I would be devastated.

In lieu of pumping, I do manual lymphatic drainage using techniques I learned from my therapist. You can find many YouTube

videos demonstrating these techniques as well. I also do the Dead Cat Shake, which I demonstrate on my YouTube channel. To perform this oddly named exercise, lie on a bed with one leg in the air and then shake it for a minute or two. After that, switch to the other leg -- this helps move the lymph up and out. I always take a few extra minutes in the shower or bath to do an extra lymphatic massage.

While you're on YouTube, another resource is the many therapists who have demonstrated simple lymphatic yoga routines there. Many of these routines are performed while sitting in a chair or even lying in the bed. I've found these to help reduce swelling, help me get a good stretch in, and to be relaxing as well. I hope you enjoy lymphatic yoga too. Just go to the YouTube search area and type in lymphatic yoga, or yoga for lipedema and you will find many videos from which to choose.

Be prepared with powder if you're traveling to someplace hot. Rolls and folds are miserable and can get irritated if you're sweaty, so apply powder the second you start getting that unfresh, rubbing, or burning feeling!

Elevation of the legs is your best friend on travel, anytime and anywhere you can. Use your suitcase to prop your legs up during layovers, elevate on the plane if you can figure out a way, and elevate when you to your hotel room. On long flights do what you can to move your legs. This includes getting up and walking around every hour you're awake, and massaging your legs whenever possible. On longer flights you can perform a massage in the lavatory. Do circles, leg raises, leg stretches, and anything you can to move your legs. The more movement you perform the less likely you are to experience swelling and blood clots.

If you're traveling for surgery, ask for wheelchair assistance on the way home every time. You never know how long the walk is going to be in different airports. I travel to LA, and the Phoenix airport is often one of my stops. That airport is GIGANTIC, and the walk would not have been possible after surgery for me. Also, last minute terminal and gate changes that can send non-recovering people running, so be prepared and unashamed. You've had surgery for Pete's sake! It is OK to get the wheelchair!

Happy traveling and don't let yourself be stuck at home. The world is your oyster!

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## One Last Note about Fitting In

*“Comparison is the thief of joy.”*  
~Theodore Roosevelt

Thinking I’m like or not like other people has been one of the areas I struggle with, and probably always will. I’ve had therapy about it. I’ve mentioned that in my life I’ve felt, “less than” others, and even not like a real woman. I choose now to believe that I am equal, beautiful, needed, wanted, desirable, and yes, a real woman.

Please know that up to 11% of women have lipedema, and that a recent study shows that the average adult American woman now wears between a misses size 16-18 and a plus size 20W.

And if you ever have time to watch a movie, I encourage you to watch a video by Rachel Hollis. In it there is an activity at her conference called *Stand up for your Sister*, where women check boxes on a tough questionnaire that asks deeply personal questions. The completed surveys are mixed up and passed out again, and when the questions are called out, each woman stands for the answer on the paper she received anonymously.

One of the questions was, “I hate my body.” If you see this part in the movie, it will make you cry to realize that the vast majority of women in the room stood up for their sisters when this was asked. The vast majority of women in the audience hated their bodies!

Think about that for a second the next time you are at a public pool. Look at all the women there – the tan model types, the grandmas, the young tweens just figuring out life, the ladies with lipedema, the new mothers, all of them. Some of them will be trying to cover up their bodies and some won’t, but just know most of them, if asked, might tell you they don’t like or even hate their bodies. We are not that different from women we would classify as normal or beautiful.

With all of this, smile, hold your head high, keep your shoulders back and know you’re not alone. You are beautiful, you are special, and you feel things about your body that many other women do. You belong, and you do fit in.

## Chapter 10: Don't Let your Guard Down!

*"I wish I had known that lipedema was even a thing and it could have been managed prior to me losing my mobility."*

*~ Member of online lipedema community*

Here is a bottom-line fact: until a medicinal cure is discovered, if you have lipedema now, you will always have lipedema. Even if you have surgery, you still have the genetics of someone with lipedema, and if you don't manage it, it could come back. So don't let your guard down, and keep managing it for life.

If you decide to not pursue aggressive treatments like surgery there are still things you can do each day to keep your lipedema in check. Be watching latest research on diet. We know that removing sweets from our diet is important, but research also shows that anti-inflammatory and keto diets have can help manage swelling as well. One thing you can do right now is to reduce your sugar intake. This really can keep inflammation and swelling at bay, which in turn slows progression of the disease.

Exercise! It doesn't have to be anything crazy or over the top. In fact, gentle exercises are wonderful. Swimming is my best recommendation not only because it's easy on the joints and feels good, but it also offers natural compression from being in the water. Hey, it's time you don't have to wear compression! Could you get in even a few days a week of something light like this? It will help!

Another exercise I love that you can do it today is lymphatic yoga. If you go to YouTube and search for "lymphatic yoga," you will find all kinds of videos made by licensed therapists. Many of the stretches are designed to be performed while sitting in a chair or on a bed, so you won't have to get down on the floor. Don't worry -- this isn't the crazy, leg-over-your-head type of yoga. These exercises are designed to get your blood pumping and your lymph flowing up and out. I highly recommend it.

Wear your compression as much as possible. Remember, compression doesn't have to be custom fitted or expensive. I literally buy mine from Amazon. And if what you have for compression is so miserable to wear that you find yourself making excuses for not

wearing it regularly, find different compression. The best compression is the one you will actually wear.

Get manual lymphatic drainage. Many insurances cover this procedure, and it helps to be taught in person the first couple of times by someone with lymphatic training. If you cannot see someone for MLD, this is something you can do yourself. There are many videos of how to do MLD for lipedema online. It is a quick, easy, and free thing you can do today. I incorporate MLD into my morning shower routine every single day to save time. And remember to do deep breathing exercises while you're getting or doing MLD. This also helps the lymphatic system flush it out.

Also, look into other things like dry brushing and using vibration plates and rebounders to stimulate lymphatic flow. The vibration plates are devices that you stand on, or put your feet on while sitting for a period of time and what they do is shake, shake, and shake in different patterns. A rebounder is basically an in-house trampoline that you jump on for a period of time, and a dry brush is literally a brush you buy and use gently on your skin in light strokes to stimulate lymphatic flow up and out.

There are entire Facebook groups dedicated to using vibration plates, with experts leading discussions and sharing videos. They also have many testimonials and reviews of models to try for your particular situation. I highly recommend that you look into this group before buying a vibration plate. Likewise, there are tutorials and one page aids online (just google it) for how to dry brush, and how to rebound for lymphatic flow.

These things take time and money, but they are all at home solutions that you can purchase and begin using now. P.S.: if you have bad knees, research the plates and rebounders before making a purchase

Lastly, stay on top of your emotions with this disease. If you have access to a counselor, lipedema and its impacts to you would be a great topic of discussion. But again, there is so much online that can support you – free. Websites like [LegsLikeMine.com](http://LegsLikeMine.com), Facebook, Instagram, Twitter and Pinterest have so many options you could never visit them all and interact with all who are there to help. Simply put in the search term LIPDEMA in the media of your choice and go for it! Of course, now too, there are all kinds of online support areas available, like [betterhelp.com](http://betterhelp.com), where you can speak to a trained therapist from home. What a wonderful opportunity if you're not feeling like getting out!

And remember that emotional stages we all can get stuck in, like anger and blame, may actually cause cortisol releases with

stress, and could inflame your lipedema. So do what you can to manage that stress and stay calm!

One of the best things you can do for your own mental health is to simply come to peace with the fact that you have lipedema (much easier said than done!). Accept your condition and take action and responsibility, not only for yourself, but for others. This is no time for denial to win the battle. Lipedema is not a disease we asked for, and it's not fair, but the sooner you accept the fact that you have lipedema, the sooner you can begin seeking treatment and learning to live your best life with this condition.

My confidence and courage have increased so much because of the support and sense of community I've received through numerous other women in the support groups and online who have been courageous enough to share their stories and images. I finally realized I am not alone and know that I need to normalize what it looks like to be one of the 11% of women with lipedema by showing my legs and letting folks know they aren't alone either. I know I don't look "normal" in shorts or skirts, but it's the best my legs are ever going to look! I cannot tell you how strongly I recommend reaching out for support from other people with legs like ours. It will make a tremendous difference in your life, as it has done in mine.

If you have daughters, watch their legs closely. If you see any symptoms of lipedema forming during times of hormonal change, get them to the doctor as soon as possible to begin a regimen of treatment and see about a clinical diagnosis. The earlier the condition is detected, the more you can prevent progression and receive treatment. We do not want our daughters to go through what we've been through. Now that we know about it, it's our responsibility to share and help others.

I hope you will take time to share your story and educate your medical providers in your journey. And if you see someone who may have lipedema and doesn't know it, I hope you will have the courage to tell them in a discreet way so that they can find some help as well.

Do not let this disease get the best of you! Keep moving, keep living, and stay active!

# Chapter 11: You are Not Alone

According to an article in the National Institutes of Health by Donald W. Buck and Karen L. Herbst, lipedema is believed to affect nearly 11% of adult women worldwide. If that statistic is accurate, it means that millions of women are affected. Based on my own personal experience, I suspect many of these women are undiagnosed and untreated.

The moment that I finally got the clue I needed to figure out I had lipedema was huge for me, and when I got on the phone with my lipedema surgeon the first time, and he looked at my pictures and history and gave me the official diagnosis, I was totally overwhelmed with a lot of emotion – relief, and validation being two that come to the top of my mind. When I got off the phone, I cried, knowing that my gut wasn't wrong and that all those years of crazy diets and exercise and surgery that didn't work suddenly made so much sense.

Right now, women all around the world just like us are wondering what the heck is wrong with their bodies, why they can't be like other women, why they haven't got the desired results from diet and exercise. Many (if not all) feel some level of isolation, shame, and embarrassment from their situation and do what they can to keep their bodies covered up. It could have been your mother or grandmother, and it could be your daughter.

As I was gathering quotes, pictures, and stories from our contributors, the emotion of all the past years hit me. Hearing the sadness and desperation from women with legs like mine really brought home what we've all been through. There are so many women like us, who need our help, to just have that one chance to hear the word "lipedema" so they can begin to work on feeling and getting better, both physically and emotionally.

I hope you will consider sharing your story with someone, and be brave enough to use social media as a way to get the word out. If someone can just hear the word, they can start on their journey sooner.

Be well, friends, get that bathing suit on, live life, and don't be the beautiful woman wearing jeans on a beach day any longer.

# Other Websites with Helpful Information

The Cleveland Clinic:

**<https://my.clevelandclinic.org/health/diseases/17175-lipedema#:~:text=Lipedema%20is%20a%20condition%20that,affect%20the%20hands%20or%20feet>**. The top of the game when it comes to management of lipedema and other lymphatic-related diseases. They offer information and appointments, and I love that they have statistics available online about their outcomes.

Fat Disorders Research Society:

**<https://www.youtube.com/c/FatDisordersResourceSociety>**. This channel has so many amazing presentations from leading researchers and patients at their conferences. It has been such a huge source of information for me as I dug into what was wrong with my legs. Their website is **<https://www.fatdisorders.org/>**.

The Lipedema Foundation: **[www.lipedema.org](http://www.lipedema.org)**. This website has brochures about lipedema, a patient registry, and numerous copyrighted photos of lipedema types and stages.

The Lipedema Project: **<https://lipedemaproject.org/lipedema-lipoedema-lipodem-provider-directory/>**. I'm starting you at their provider directory site. I refer people to it daily.

Lipedema Simplified: **[www.lipedema-simplified.org](http://www.lipedema-simplified.org)**. This website is the passion project of a patient and advocate named Catherine Seo. She's passionate and smart and has dedicated her time to forwarding our cause. One of my favorites because she is a patient.

Southwest Airlines Persons of Size policy:

**<https://www.southwest.com/html/customer-service/extra-seat/index-pol.html>**

Total Lipedema Care: **<https://totallipedemacare.com>**. This is the office of Dr. Jaime Schwartz (my surgeon) and now, Dr. Karen Herbst. This office and their staff are incredibly knowledgeable, and compassionate. They also were very comfortable and experienced in taking cases of patients who have a high BMI.

# Bibliography

Alberga A, S, Nutter S, MacInnis C, Ellard J, H, Russell-Mayhew S: Examining Weight Bias among Practicing Canadian Family Physicians. *Obes Facts* 2019;12:632-638. doi: 10.1159/000503751

Buck, Donald W 2nd, and Karen L Herbst. "Lipedema: A Relatively Common Disease with Extremely Common Misconceptions." *Plastic and reconstructive surgery*. Global open vol. 4,9 e1043. 28 Sep. 2016, doi:10.1097/GOX.0000000000001043

Christel, Deborah A. & Susan C. Dunn (2017) Average American women's clothing size: comparing National Health and Nutritional Examination Surveys (1988–2010) to ASTM International Misses & Women's Plus Size clothing, *International Journal of Fashion Design, Technology and Education*, 10:2, 129-136, DOI: 10.1080/17543266.2016.1214291

Dunkin, Mary Anne: Lipedema. WebMD October 18, 2021. <https://www.webmd.com/women/guide/lipedema-symptoms-treatment-causes>

Herbst KL, Kahn LA, Iker E, et al. Standard of care for lipedema in the United States. *Phlebology*. 2021;36(10):779-796. <https://journals.sagepub.com/doi/full/10.1177/02683555211015887>

Hollis, Rachel. Stand for your Sister. RISExDallas 2019. <https://www.youtube.com/watch?v=rrKlebp05Mc>

Rockson SG, Granger DN, Skeff KM, Chaite W. Lymphatic biology and disease: Is it being taught? Who is listening? *Lymphat Res Biol* 2004;2:86–95

Stutz, Joseph MD. Lipedema can be Life-Threatening. *Fat disorders research society*. May 30, 2016. <https://www.youtube.com/watch?v=p099mQyjXIQ>

White, Tracie. Biomarker for lipedema, other lymphatic diseases discovered. November 23, 2020. *Stanford Medicine News*. <https://med.stanford.edu/news/all-news/2020/11/biomarker-for-lipedema-discovered.html>

## Connect with LegsLikeMine

**Visit us Online at**  
**[www.LegsLikeMine.com](http://www.LegsLikeMine.com)**

To read blog posts, see questions about all kinds of lipedema-related topics answered, hear personal stories, and even get product recommendations for women with lipedema.



### **Join us on Social Media**

For more interaction and special content that may not be on the blog site.



**[https://www.instagram.com/legs\\_likemine/?hl=en](https://www.instagram.com/legs_likemine/?hl=en)**

**<https://www.facebook.com/LegsLikeMine/>**

**<https://youtube.com/c/legslikemine>**

**[https://twitter.com/legs\\_likemine](https://twitter.com/legs_likemine)**

**<https://www.pinterest.com/legslikemine/>**

### **Tell us what you think!**

To share your thoughts, ask a question, submit a product for review, and see what's going on in the lipedema community, please visit:

**<https://LegsLikeMine.com/subscribe/>**

**Susan O'Hara** is from Yukon, Oklahoma, and is the founder of LegsLikeMine, LLC. Susan has suffered from lipedema for more than two decades, starting with the birth of her first child in 2001. Her condition progressed slowly through various hormonal changes, but flared to a new level with a significantly stressful work-related event that served as the catalyst for seeking surgical treatments.

Like many, Susan went undiagnosed for almost 20 years, suffering pain and slowly losing mobility. Despite diet, exercise, and having two weight-loss surgeries, the condition persisted. After numerous MRIs, knee surgeries, x-rays, and a bout with tendonitis, a technician asked Susan who was treating her LYMPHEDEMA, and this got her connected to support groups, who actually saw her pictures and suggested she had LIPEDEMA.

Susan's informal, online diagnosis allowed her to begin research, finding specialists and therapists familiar with lipedema, who were able to clinically diagnose and provide treatment. Through her research she discovered compression wraps and massage techniques to help manage her condition. In 2021, Susan had three Lymph-Sparing Lipectomy surgeries, and incorporated a regular swimming routine into her life to help manage lipedema.

Susan has struggled for years to find boots, shoes and clothes that fit and help highlight features other than her legs. She has dedicated a portion of her social media presence to help others with the condition continue to find and showcase their own beauty and belonging by sharing her fun ideas in fashion in her own, fun, way.



LegsLikeMine is a work of passion and necessity in hopes that it will get information to women who badly need help and who may not know they have the painful fat condition called lipedema.