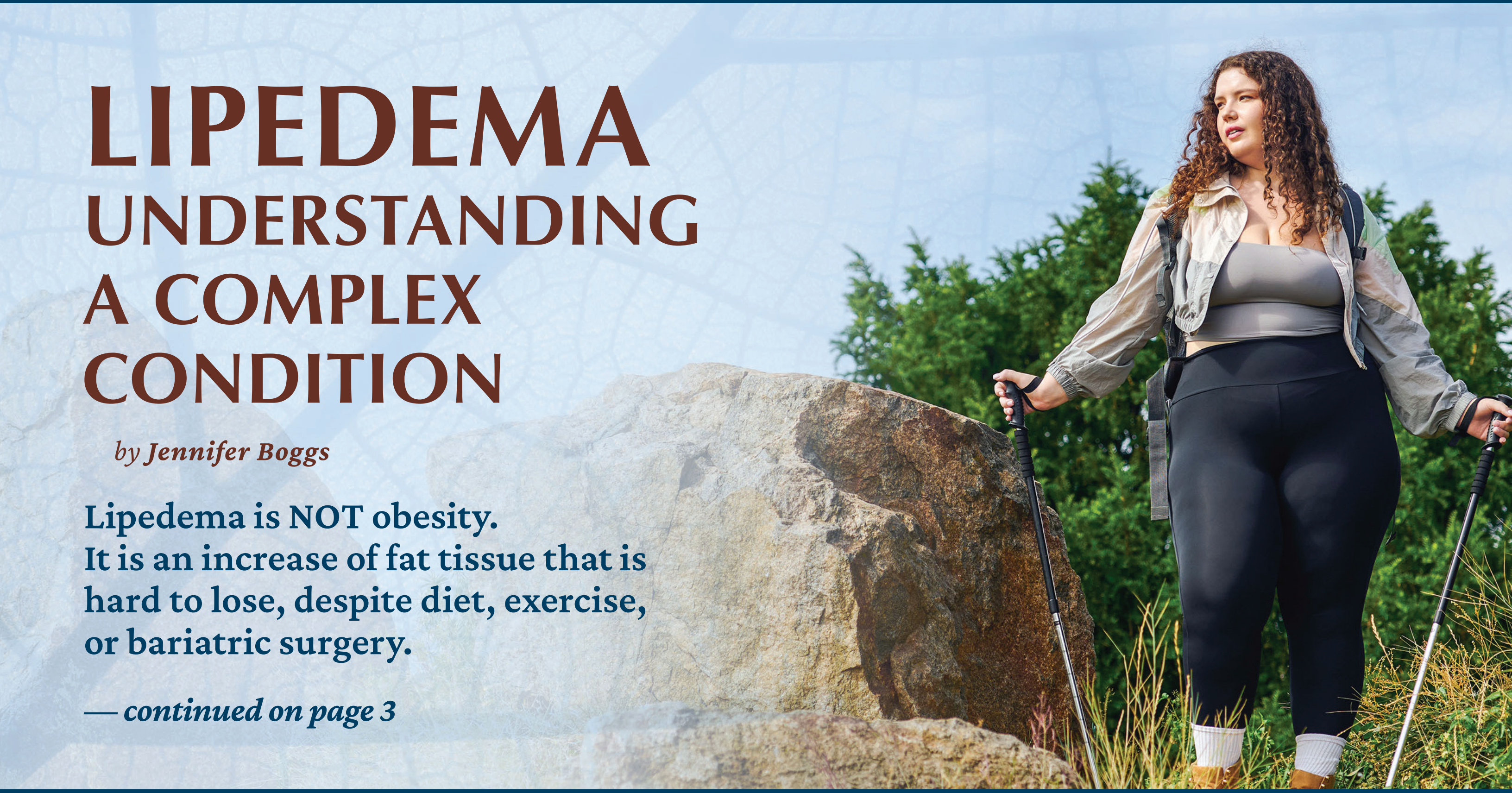
Volume 10, Issue 1

VEIN HEALTH NEWS

The vein magazine for primary care physicians and healthcare providers

VEINHEALTHNEWS.COM



LIPEDEMA

UNDERSTANDING A COMPLEX CONDITION

by ***Jennifer Boggs***

Lipedema is NOT obesity. It is an increase of fat tissue that is hard to lose, despite diet, exercise, or bariatric surgery.

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ALSO IN THIS ISSUE

5-12%
of women
are thought to be impacted by lipedema.

Lipedema knows no boundaries; the disease crosses demographics like age, race, ethnicity, and education.

LETTER FROM THE EDITORIAL DIRECTOR

Empowering patients through education

Medicine is based on science, but there's an art to it too. When diagnosing patients at the Vein Healthcare Center, we use tools like duplex ultrasound and venous reflux tests to determine whether vein disease is present and to what degree. We also talk with each patient about how changes in their legs feel, their family history, and other health factors. The art is looking at a patient and their experience holistically.

In this issue of Vein Health News, we explore a condition called lipedema. Though it's not venous in nature, there is often a co-occurrence with venous issues and lymphedema.

Lipedema is estimated to affect 10 to 17 million people in the United States, primarily women. The true prevalence is likely higher due to widespread underdiagnosis. The good news is that in 2021, a group of experts in the U.S. released a "consensus guideline" to standardize care for this diagnosis. Evolving scientific research is helping to increase knowledge of and about the condition.

At our practice we see a number of patients who have lipedema, and we do everything we can to provide knowledge to understand the condition. Education and resources are essential for managing lipedema — including the difficult emotions that can arise after diagnosis.

There is no cure for lipedema, but there have been advancements in management, including graduated compression, Manual Lymphatic Drainage (MLD), medications like GLP-1 and GIP agonists, and surgical intervention. There are ways for people with lipedema to feel better and improve their quality of life. You can read about one woman's experience in our regular column, "One Patient's Perspective."

The art of medicine also involves conveying complex information to patients so that they can become their own advocates. We hope that the information in this issue can be a way for both patients and providers to better understand a complicated condition.

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*VEIN HEALTH NEWS was founded by Dr. Cindy Asbjornsen to further vein health education and understanding. It is available at no cost to primary care physicians, healthcare providers, and the public. To subscribe, or to request advertising information, please email **info@veinhealthnews.com**.*

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LIPEDEMA SNAPSHOT

Lipedema is a common yet under-diagnosed chronic medical condition that primarily impacts women.

Symptoms tend to occur at times of hormonal change, such as puberty, pregnancy, and menopause.

Lipedema is characterized by a buildup of fat in the limbs; tissue texture can feel like rice, beans, or walnuts.

Additional symptoms may include pain, easy bruising, sensitivity to touch, leg heaviness and fatigue, swelling, and impaired mobility.

KEY CONSIDERATIONS

1. **It's Not Your Fault**
   Lipedema is a medical condition not caused by lifestyle choices, although symptoms can be exacerbated by poor diet and lack of exercise.

2. **Early Action Matters**
   The sooner you understand and manage your symptoms, the better.

3. **Support is Essential**
   Real relief starts with the right team.

4. **Your Body Deserves Compassion**
   You are allowed to move at your own pace, and to listen to your body.

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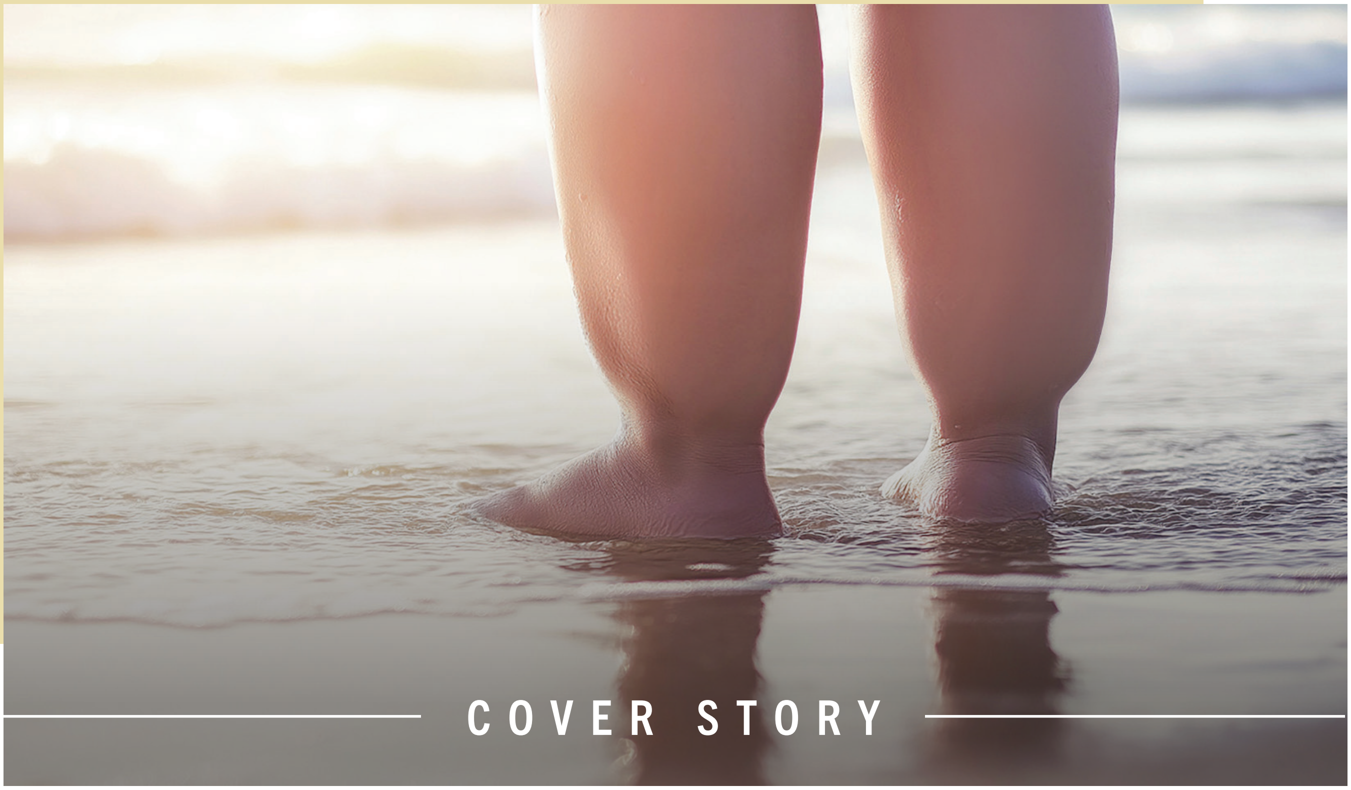

LIPEDEMA: SHEDDING LIGHT ON A MISUNDERSTOOD DISEASE

by Jennifer Boggs

— continued from cover

Lipedema differs from obesity in fat cell behavior, potentially involving genetics and hormones. Medical diagnoses are not always obvious, especially when symptoms are complex, varied, and can easily be mistaken for other conditions. Lipedema (pronounced lai·puh·dee·muh or lip·puh·dee·muh) is one such condition. It is often confused with lymphedema, obesity, or cellulite. Adding to the complexity, lipedema can co-occur with other conditions, such as venous disease.

Although often misdiagnosed or underdiagnosed, lipedema is quite common. Lipedema is a clinical diagnosis, and there are currently no blood tests or imaging studies that can confirm it.

Research into the diagnosis and management of lipedema continues. In 2021, a group of experts released a "consensus guideline" creating a standard of care for lipedema in the U.S. This and other research are helping to advance understanding towards early diagnosis, treatment, and hopefully one day, a cure.

What is lipedema?

Lipedema is a loose connective tissue disorder that results in an abnormal buildup of adipose (fat) cells in the limbs. These cells settle into certain areas of the body, most often in the hips and legs—disproportionately more significantly than in the upper body (although lipedema sometimes affects the arms and lower trunk). Areas affected by lipedema tend to be symmetrical, while the hands and feet are typically spared.

Someone with lipedema may experience pain, tenderness, swelling, or easy bruising of the affected areas. The intensity and frequency of pain can vary. The condition may be accompanied by an unusual lumpy or fibrous texture within the fat tissue that can feel like peas or walnuts beneath the surface of the skin.

The cause of lipedema is unknown, though it is believed to be hereditary. Research is underway to determine the biological role of genetics, hormones, inflammation, and metabolism in the condition's development. Several genes have been implicated, most notably the mutated gene AKR1C1.

Lipedema occurs almost exclusively in women, and about 5-12 percent of women in the U.S. are affected. Studies have shown that it often runs in families on the mother's side.

Signs and symptoms

Symptoms of lipedema vary from person to person and may worsen over time. Lipedema can develop at any age, but most symptoms seem to develop (or worsen) during periods of hormonal change such as puberty, pregnancy, or perimenopause, or sometimes when a person takes hormonal birth control.

Major trauma, gynecological surgery, and significant periods of stress can also trigger lipedema.

Common symptoms include:

- Excess fat that builds up in the lower extremities, causing buttocks, hips, thighs, and calves to become significantly larger than the upper body
- Fibrous tissue within the fat that may feel like lumps beneath the skin
- Pain, ranging from mild to severe, that is constant or occurs only with pressure

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COMPARING LIPEDEMA WITH SIMILAR CONDITIONS

LIPEDEMA	VS	OBESITY
Extremities sparing hands / feet, can include abdomen	AREAS OF EXCESS WEIGHT DISTRIBUTION	Entire body
Yes, especially at later stages	PRESENCE OF NODULAR FAT	Less common
Frequent	TENDENCY TO BRUISE	Less likely
Common	PAIN ASSOCIATED WITH FAT	Rare
Common	RESISTANT TO DIETARY INTERVENTIONS AND EXERCISE	Less likely
Less common	ASSOCIATED WITH METABOLIC OR CARDIAC RISKS	More common

LIPEDEMA	VS	LYMPHEDEMA
Bilateral and symmetrical	APPEARANCE	Often unilateral, may appear bilateral yet is often still symmetrical
Non-pitting	PITTING (INDENTATION REMAINS WHEN PRESSURE IS APPPLIED)	Involves pitting edema
Fat deposits and possible swelling in arms / legs, not hands / feet	PRESENTATION	Fat deposits and swelling of limb(s) including hands / feet
Rare	SKIN INFECTIONS / OPEN WOUNDS	Common

Credit: The Lipedema Foundation

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- Swelling or dimpling around the affected areas
- A sensation of heaviness or fatigue in the legs
- Skin that bruises easily (ecchymosis)
- Feet/hands are typically spared, sometimes appearing like an ankle or wrist "cuff"

What lipedema is not

For many people, lipedema is not the first diagnosis offered for their array of symptoms. They may think that their weight gain or shape of their bodies is due to obesity or something else. To that end, let's first discuss the conditions that lipedema is not.

Lipedema is often confused with obesity, but is quite different. Obesity-related fat occurs throughout the body, while in lipedema, the fat occurs in the limbs (and sometimes lower trunk), typically sparing the hands and feet. People with early-stage Lipedema typically do not have conditions that are more commonly associated with obesity such as diabetes, high cholesterol, or high blood pressure.

Another distinction is that lipedema is resistant to diet, exercise, and bariatric surgery. While the disease can be exacerbated by obesity, there are many women who have lipedema and are not obese.

Lipedema is often mistaken for lymphedema, a chronic condition that causes swelling in body tissues due to a buildup of lymph fluid. The swelling in lymphedema often affects only one side of the body and includes the hands and feet.

Lymphedema can be diagnosed with the help of imaging or genetic tests. There are no definitive tests for lipedema, so diagnosis is based on patient history, physical examination, and ruling out other disorders. Lymphedema can occur secondary to lipedema, as the accumulation of fat cells in the tissues can lead to inadequate lymphatic drainage and cause swelling.

If someone with lipedema also has lymphatic system dysfunction, they may also present with lymphedema. If they have both conditions together, it is called "Lipo-lymphedema."

Diagnosis and treatment

Because there are not yet standardized tests to confirm lipedema, like biomarkers, blood, urine, or imaging tests, diagnosis is clinical. That means a lipedema-informed physician evaluates a patient's medical history and performs a physical examination. In addition, some rehabilitative therapy professionals may be trained in distinguishing lipedema from lymphedema.

Sometimes diagnosis of (and treatment for) co-occurring conditions such as lymphedema or venous insufficiency can help to add more pieces to the diagnostic puzzle.

There is currently no cure for lipedema. Present treatment means management, which includes dietary changes (to reduce inflammation), exercise, compression, weight loss (for management of comorbid metabolic disease), Manual Lymphatic Drainage, pain management, physical therapy, and in some cases, surgery.

Treatment for comorbidities can sometimes help. For example, treating underlying venous insufficiency is appropriate if it is contributing to lower leg symptoms that impair functioning.

Having lipedema can be physically painful, not to mention difficult to cope with emotionally. That's why psychological and social support are just as important as physical treatment. Education about the condition is an excellent place to start. ■

A CLINICAL PERSPECTIVE ON LIPEDEMA

Lipedema is not a rare disorder, but due to lack of research and general awareness, a proper diagnosis is often delayed. Fortunately, recent scientific research and growing patient awareness are helping to increase knowledge of and about the condition.

Diagnosing lipedema

In May 2021, a committee based in the U.S. published a consensus guideline for the standard of care for lipedema. The three key aspects of diagnosis are listening to a patient's family and medical history, physical examination, and ruling out possible causes of symptoms.

Patient history—Clinicians should complete a detailed history with the patient. Noting such things as:

- Medical history
- Family history of similar body type (to consider heredity)
- Difficulty losing fat in affected areas
- Onset/worsening at time(s) of hormonal change
- Pain, tenderness, heaviness in affected areas
- Tendency to bruise easily
- Decreased functional ability (including mobility)
- Decreased quality of life
- History of joint issues
- Symptoms persist despite: elevation, nutritional interventions, exercise, diuretics, bariatric surgery

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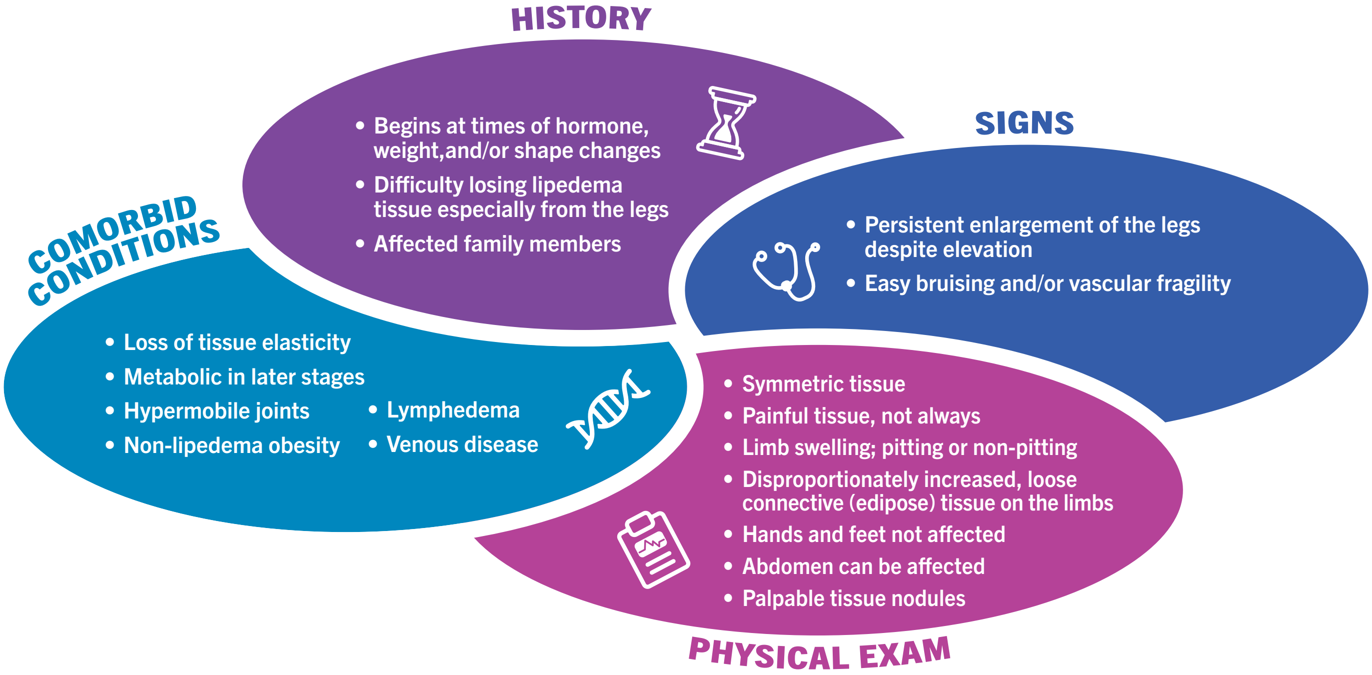


HISTORY

- Begins at times of hormone, weight,and/or shape changes
- Difficulty losing lipedema tissue especially from the legs
- Affected family members

SIGNS

- Persistent enlargement of the legs despite elevation
- Easy bruising and/or vascular fragility

COMORBID CONDITIONS

- Loss of tissue elasticity
- Metabolic in later stages
- Hypermobile joints
- Non-lipedema obesity
- Lymphedema
- Venous disease

PHYSICAL EXAM

- Symmetric tissue
- Painful tissue, not always
- Limb swelling; pitting or non-pitting
- Disproportionately increased, loose connective (edipose) tissue on the limbs
- Hands and feet not affected
- Abdomen can be affected
- Palpable tissue nodules

Diagnostic considerations for lipedema supported by the U.S. Standard of Care Committee

— *continued from page 6*

Physical Examination—An exam includes visual inspection and physical palpation. (A Stemmer sign test is also recommended to assess for co-morbid lymphedema.) Take into consideration the location and symmetry of adipose tissue.

VISUAL INSPECTION

- Bilateral, symmetrical fat accumulation that can appear in a combination of the legs, buttocks, hips, arms and/or lower trunk
- Disproportion between upper and lower body
- Lobules of fat may present at hips, medial knees, lateral malleoli, or above elbows
- Presence of raised ridge/fold of fat, possibly a "cuff" at wrists and ankles

PALPATION

- Presence of nodular and/or fibrotic texture in affected areas
- Lipedema tissue texture can vary widely; It may feel like fluffy fat with nodules embedded in it, have a dense, cement-like texture, feel granular or grainy, or even have a spongy texture
- Nodules may feel like rice, peas, or walnuts
- Fibrosis may feel dense, firm, woody, putty-like, or cement-like
- Pain/tenderness in affected areas
- Cutaneous hypothermia may be present; skin may feel cool to the touch

STEMMER SIGN TEST

Lipedema typically spares the hands/feet and presents with a negative Stemmer sign. However, a positive sign does not rule out lipedema but likely indicates the presence of Lymphedema. (If both conditions are present, this is termed "Lipo-Lymphedema.")

Performing the test: pinch the skin on the back of the second toe. If you cannot create a fold of pinched skin, this results in a positive sign for lymphedema.

If you can pinch, the Stemmer sign is negative, and lymphedema is likely not present.

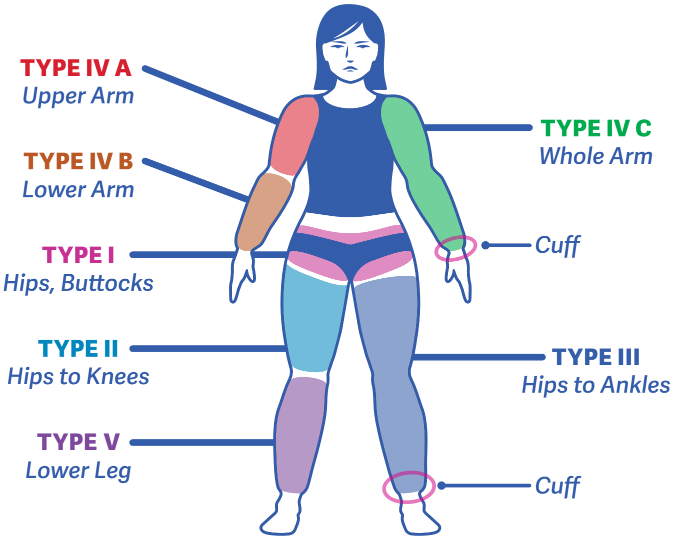
Part of diagnosis is eliminating other possible causes of symptoms. Review of comorbid conditions include obesity, lymphedema, hyper-mobile joints, loss of tissue elasticity, and vascular or venous disease.

Different types and stages of lipedema

Lipedema is divided into five types based on the location of fat deposits, and the different types can overlap.

- Type I: Between the umbilicus and hips/buttocks
- Type II: Between the pelvis and knees
- Type III: Between the pelvis and ankles
- Type IV: Between the shoulders and wrists
- Type V: Between the knees and ankles

TYPES OF LIPEDEMA



Lipedema also has five stages based on the severity of the fatty deposits and problems they cause.

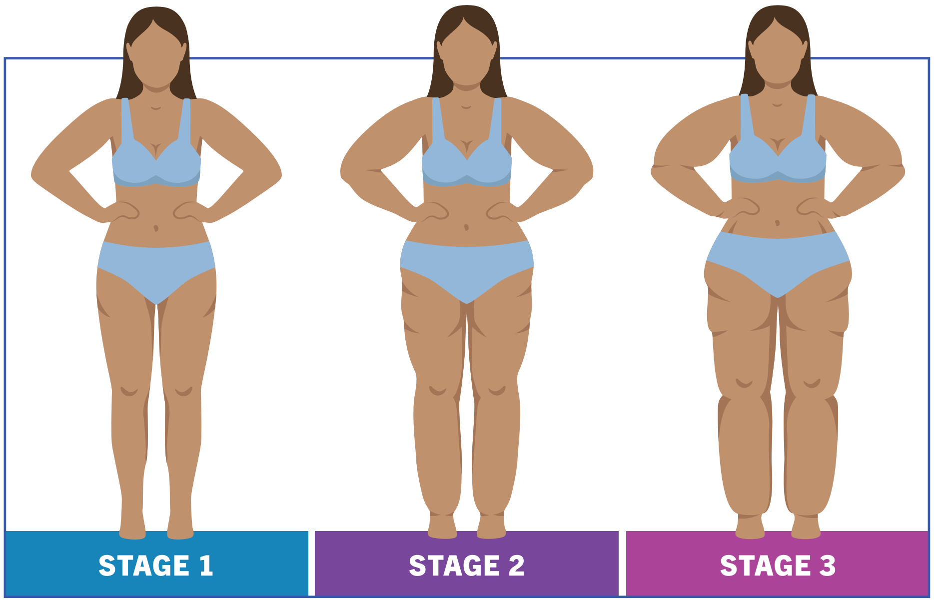
- Stage 1: Skin is smooth but there are pockets of enlarged fat tissue.
- Stage 2: Skin is uneven with indentations and large mounds of fat tissue can be seen and felt.
- Stage 3: Large amounts of fat tissue cause deformation, typically around thighs and knees.

Consider the emotional aspect

Lipedema is a difficult condition to live with. In addition to the physical pain, many women have had to cope with their perceived failure to lose weight by typical methods. This can increase the incidence of depression, anxiety, and/or eating disorders.

Therefore, clinicians should offer people with lipedema a mental health consultation as part of their treatment, especially when there are signs or symptoms of the negative emotional impact of lipedema. Improving one's mental health has been proven to increase self-care by women with lipedema. ■

STAGES OF LIPEDEMA



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https://www.lipedema.org/clinicians-guide

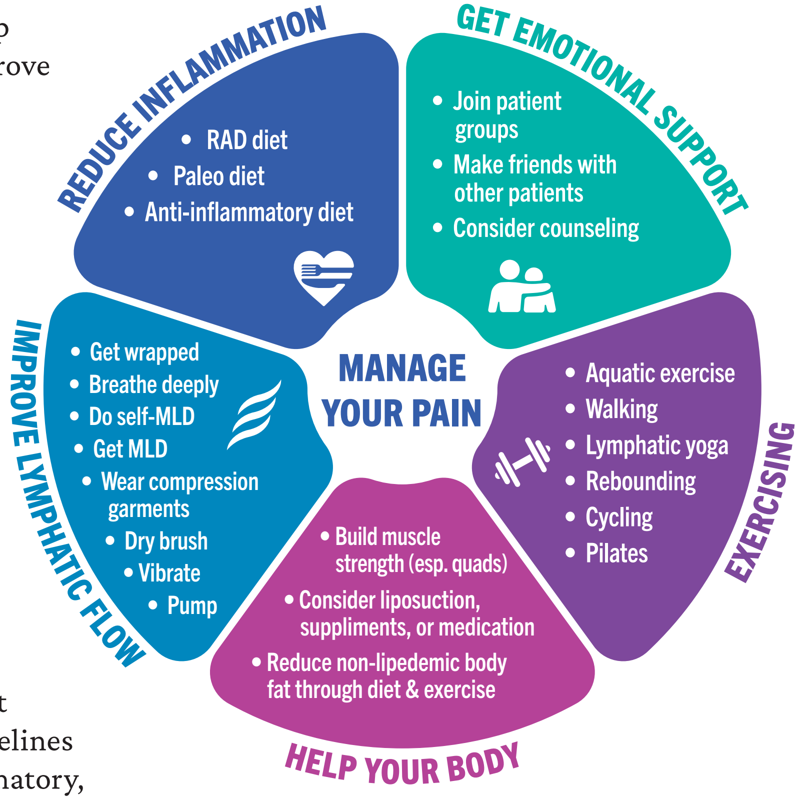
LIVING WITH LIPEDEMA: EFFECTIVE MANAGEMENT AND CARE

by Benjamin Lee

Lipedema is a complex condition. While there is not yet a cure for lipedema, there are an array of treatment options that can help patients manage their symptoms and improve their quality of life.

According to Robin Dobrinick, Nurse Practitioner at the Vein Healthcare Center, taking a multimodal approach is the most effective. “We recommend that patients employ a variety of treatment modalities, starting with conservative and minimally invasive management strategies before considering surgical intervention,” said Dobrinick.

HOW TO MANAGE LIPEDEMA



CREDIT: The Fat Disorders Resource Society.

Dietary changes

Even though lipedema fat is resistant to weight loss from dieting or even bariatric surgery, what one eats is still an important component of treatment. The dietary guidelines that yield the best results are anti-inflammatory, such as ketogenic or low-carbohydrate diets. Diets high in refined carbohydrates, hydrogenated vegetable oils, fatty meats and high-fat dairy are associated with inflammation, which can exacerbate symptoms of lipedema.

Exercise

Moving the body is essential for managing lipedema symptoms. Exercise also helps the lymphatic fluid move through the lymph system.

Pain from lipedema can make exercise challenging, so try low-impact activities like swimming, water aerobics, walking, and moderate stretching. Yoga and Pilates can help with flexibility, core strength, and lymphatic drainage. Resistance training with light weights, resistance bands, or bodyweight exercises can help strengthen muscles and also supports the lymphatic system.

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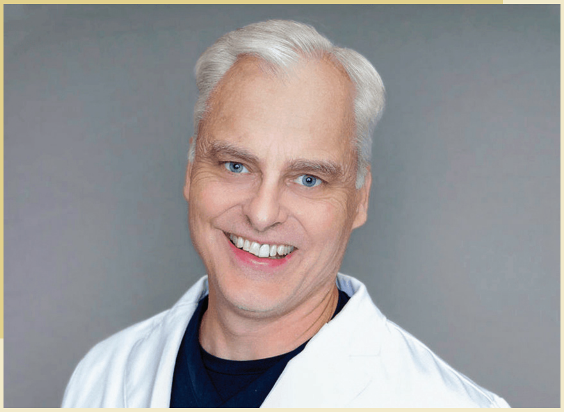

Q&A with Dr. Thomas Wright

Dr. Thomas Wright, MD, FAVLS, RVT, is the medical director of Laser Lipo and Vein Center in St. Louis, Missouri. Dr. Wright has been treating patients with lipedema for more than 20 years and has a deep understanding of the disease.

Why do patients with lipedema seek a surgical solution?

The simplest reason is having lipedema symptoms or morbidity from lipedema that is not fully managed with non-surgical means. A modified type of liposuction can reduce bulk tissue which can aid in mobility, knee function, and joint mechanics.

What steps would you recommend before surgery?

Lipedema needs to be treated comprehensively, including an anti-inflammatory diet and daily wearing of medical grade compression. It's important that these non-surgical treatments are implemented before surgery, when their effects can be fully appreciated.

What are the success rates of lipedema surgery?

The randomized controlled study of lipedema surgery, called the LIP LEG study, showed over 70% of women with lipedema who underwent lipedema liposuction had significant improvement in pain and quality of life versus 10% of women in the conservative control group. The results of this study show a 26:1 odds ratio of significant improvement for those who had surgery. This should favor most women with lipedema to consider surgery.

Who is this modality most effective for?

Lipedema reduction surgery or lipedema liposuction is effective for smaller patients in reducing pain and swelling and potentially halting progression, and larger patients with more advanced stages can also benefit with more significant improvements in mobility and quality of life.

Is there any type of patient that you would advise against having surgery?

Surgery is not for everyone, and patients with significant medical issues that make the risks of surgery greater than the likely benefits should not have the surgery. In my practice, active coronary artery disease, other heart conditions, and type 1 diabetes are not recommended for surgery because of the surgical complication risks. They should manage this disease conservatively. Also, very early Stage 1 lipedema with few or no symptoms often can be managed without surgery. Everyone else who is in good health overall should consider surgery if their symptoms are not controlled with diet and compression.

How many treatments does it typically take?

Lipedema surgery on the legs typically takes three surgeries to treat completely, though on smaller patients they may only require two. If arms are involved, they can usually be treated in one surgery, and if the trunk is involved, it will be an additional surgery. The number of surgeries needed by a patient varies, but it can be up to five surgeries to treat all of the areas affected by lipedema.

What does post-op care look like?

The most important part of post-operative care is strict compliance with wearing compression, and making sure the compression garment is worn smoothly without creases. Post-op drainage can last a week or two. Some patients can return to work within a few days, and some may take a week.

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— Q&A continued from page 10

Would you describe surgical intervention as a "last resort"?

No, I don't believe liposuction should be left as a last resort. It can substantially improve the lives of women suffering from lipedema and should not be withheld until they have developed complications.

Is liposuction a cure for lipedema?

Lipedema surgery is not a cure for lipedema. It can improve mobility, reduce pain, and increase quality of life, but it can only reduce the lipedema tissue; some fat tissue will remain. Lipedema must be treated comprehensively with lifelong adherence to diet and other lifestyle changes, including regular use of compression and weight maintenance to guard against regrowth or progression.

How can someone find the right surgeon to perform lipedema liposuction?

While there are more surgeons offering treatment for lipedema than ever before, many of them do not have a great deal of experience treating lipedema, or have a deep knowledge of the disease. The burden of lipedema disease is great and there needs to be more experienced, qualified surgeons who will treat lipedema comprehensively to ensure the best outcomes for their patients. Surgery is but a part of ongoing disease management. Patients considering surgery should ask practitioners lots of questions and advocate for the best care.

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Like with any lipedema treatment, start slowly and gradually increase the intensity and duration—and stay hydrated by drinking plenty of fluids during and after exercise.

Compression

Graduated compression therapy is essential for managing lipedema symptoms and is considered a first-line intervention. Compression improves mobility, reduces pain and swelling, and improves limb shape and comfort.

According to Tom Musone, Marketing Director at Juzo USA, compression will vary depending on patient presentation, pain, and physical ability to don and doff garments or compression bandages. The therapist or fitter needs to carefully select the correct compression garments depending on the lipedema stage and size of the patient.

"If there are many lobules or deep skin folds present, it may be necessary to combine types of garments," said Musone. "For example, an adjustable compression wrap or flat knit knee-high or thigh-high, paired with the Juzo Sensation capri or shorts style can also be combined with a lower-leg garment."

Manual Lymphatic Drainage

Manual Lymphatic Drainage (MLD) is a specific, gentle massage technique to stimulate the lymphatic system and move fluid out of affected tissues. A trained CLT, or Certified Lymphedema Therapist, will often teach patients the techniques required so that they can perform self-massage to help manage their condition.

Better lymphatic flow can improve limb function and overall mobility. It can slow the progression of lipedema and the development of secondary lipo-lymphedema.

MLD is a component of Complete Decongestive Therapy (CDT), a multi-modal approach that includes compression therapy, specific exercises, and skin care. Though originally used in lymphedema treatment, CDT can also help manage the painful swelling and fatty tissue accumulation associated with lipedema.

It's important to note that CDT is not effective for all stages of lipedema. For example, CDT may have limitations in Stage III of lipedema due to significant fibrosis and skin changes.

A multimodal approach to treatment includes Manual Lymphatic Drainage, dietary changes, exercise, and graduated compression therapy.

Pain management and medication

Certain medications, both prescription and over the counter, may decrease swelling or inflammation, or provide relief from pain:

GLP-1 and GIP agonists—These have potential to reduce pain, inflammation, and discomfort in some lipedema patients, even before significant weight loss occurs.

Stimulant medication—Some medications used to treat ADHD and binge eating disorders may help improve lymphatic drainage.

Metformin—This medication can reduce inflammation and fibrosis in fat tissue, and should be considered for patients with co-occuring metabolic disease.

Ketoprofen—This non-steroidal anti-inflammatory prescription medicine is not associated with increased lower extremity swelling like other NSAIDS such as ibuprofen and naproxen.

Diosmin MPFF—This concentrated citrus extract reduces inflammation in blood vessels and lymphatic vessels.

Turmeric/Curcumin—Turmeric is an antioxidant with a wide range of anti-inflammatory properties. Curcumin is a biologically active polyphenolic compound found in turmeric.

Patients should discuss any medications or supplements with their primary care physician. Be aware of any side effects or contraindications (specific reasons to avoid a particular medication), including any medicine that can contribute to weight gain or lower extremity edema.

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Complementary and Alternative Treatments

In addition to evidence-based methods of management, there are other noninvasive options that can be used to supplement traditional care.

Dry brushing involves using a firm, natural-bristle brush on dry skin in long and gentle strokes everywhere on the body except the face. With roots in Ayurvedic medicine, dry brushing improves blood circulation and promotes lymphatic drainage to reduce swelling and discomfort, similar to MLD.

Dry brushing is typically done before bathing and should be followed by a moisturizer to keep the skin supple, especially for women who routinely wear compression for lipedema.

Deep, diaphragmatic breathing has many benefits for those with lipedema. Breathing in a way that causes a deep expansion and contraction of the diaphragm stimulates the lymphatic system, massages the internal organs, and encourages the body to rid itself of toxins.

Above all, targeted breathing reduces stress and anxiety. This is especially important for fat disorder patients, because stress is a major trigger for symptoms. Practices that focus on the breath, such as Tai Chi and yoga, have been shown to be effective and relaxing.

Bathing in Epsom salt can reduce tension and swelling, and the magnesium in the salts can help to relax muscles. Certain essential oils may relieve neuropathic pain, including helichrysum, clove, peppermint, sweet birch, black pepper, blue cypress oil, and lavender. Aroma therapy can also be an effective and gentle facet of pain management.

Remember to consult with your primary care physician before starting any new treatment.

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Surgical interventions

The three most studied surgical techniques to remove lipedema tissue are tumescent liposuction, water-assisted liposuction, and power-assisted liposuction. All three depend on the tumescent technique, which involves introducing large volumes of solution into the fat below the skin space in order to swell (tumesce) the area.

The tumescent solution contains dilute lidocaine anesthetic, which causes local numbness; epinephrine, which causes constriction of blood vessels to reduce the risk of bleeding; and saline, which causes dispersion of the adipose tissue and protects surrounding vascular structures from trauma. When the solution infiltrates the tissue, its salinity causes the fat tissue and cells to swell and hydrodissect, or separate, from the connective tissue; at that point, fat is suctioned through a thin tube (cannula).

In water-assisted liposuction, the tumescent is infiltrated with more pressure; in power-assisted liposuction, a vibrating cannula is used to assist in the removal of lipedema tissue.

In the U.S., many insurance plans require patients to attempt conservative treatments before approving coverage for surgical procedures. According to leading liposuction specialist Dr. Thomas Wright, MD, FAVLS, RVT, some surgeons will not operate unless a patient first establishes healthy routines with conservative treatments and adheres to compression therapy and dietary guidelines.

"Lipedema must be treated comprehensively, involving an anti-inflammatory diet that limits refined carbohydrates and treatment for secondary obesity if present," said Dr. Wright. "Wearing medical grade compression is crucial for priming the lymphatics prior to surgery and for re-setting the position of the skin post-op; compression ensures the best surgical outcome."

Treatment of large varicosities is also recommended prior to surgery, as they can lead to excessive bleeding. Venous insufficiency often appears in conjunction with lipedema and can result in varicose veins, leg heaviness, leg pain, swelling, and redness. In some cases, patients who have lipedema and venous insufficiency may require treatment of venous disease before they are eligible for liposuction.

Mental health and wellbeing

In addition to physical symptoms, lipedema can affect a person's mental health and quality of life. In fact, there is a high prevalence of depression and other mental disorders in patients with lipedema. This can lead to low energy, feelings of hopelessness, low self-esteem, or eating disorders.

Emotional, psychological, and social wellbeing are key aspects of overall health, so counseling may be worth considering, depending on the patient. There are also support groups where patients can learn from others currently going through similar experiences. To find these groups, go to social media and search lipedema or lipoedema (European spelling).

The Lipedema Foundation provides lipedema resources to learn more about emotional support and self-care. The Foundation suggests "joining multiple groups until you find your like-minded people." They also urge privacy of patient groups and ask that only people with the disease join them.

Your lipedema care team

Diagnosing and managing lipedema can be a long journey. The condition affects many parts of the body, so treatment often involves a variety of practitioners, to include primary care physicians, physical therapists, massage therapists, registered dieticians, vein or vascular specialists, pain management specialists, surgeons, and mental health professionals.

Educating yourself can give you the confidence to navigate treatment, ask the right questions, and develop (and modify) your care plan.

Robin Dobrinick, FNP-C, always reminds patients that they are the most important member of the team: "Many healthcare professionals are unfamiliar with lipedema. It is often mistaken for obesity, and patients are typically advised to lose weight with diet and exercise. This can be extremely discouraging, leaving patients feeling responsible for their disease and helpless for solutions," said Dobrinick. "A good history and physical exam is essential to the diagnosis. If someone isn't willing to discuss lipedema, then get another opinion, because you deserve to be listened to and respected." ■

ONE PATIENT'S PERSPECTIVE

BECOMING YOUR OWN ADVOCATE

Many patients with lipedema do not know they have lipedema—and many doctors aren't familiar enough with the condition to diagnose it.

Katie, 42, says she had "normal legs" as a kid, that when she entered adolescence, "turned into columns." Her legs began looking like the "family legs" her mother and other family members had.

Still, Katie was an active teenager, playing for the state soccer team, and participating in rugby, basketball, and downhill skiing. She remembers having "giant legs" but being very thin on top. Every doctor told her to lose weight, even though she ate very little: "I went to a nutritionist and tried every diet drug under the sun, but they kept telling me that it was me; they just did not believe me."

After venous treatment did not alleviate all of Katie's symptoms, she was further evaluated and diagnosed with lipedema.

When Katie got pregnant with her son eight years ago, her legs got even bigger—and they never got smaller. After pregnancy, her legs constantly hurt, so tender that she couldn't even get a massage without pain. They felt like "cement blocks" and even doing normal activities like cleaning the house, she had to put her legs up, as they started to hurt and swell.

About two years ago, Katie's right leg "blew up" so painfully that she went to the ER to make sure it wasn't a blood clot. They suspected venous insufficiency and referred her to the **Vein Healthcare Center** in South Portland, Maine. There, Katie underwent a comprehensive evaluation and then endovenous laser ablation (EVLA) to treat her faulty veins. It helped with swelling, but it was clear that there was something else going on.

Diagnosis–and relief

At the vein clinic, Katie met with Nurse Practitioner Robin Dobrinick. After venous treatment, Robin identified that with Katie's history and symptoms, she was likely suffering from lipedema. She educated Katie on the basics of lipedema and introduced her to a wealth of resources to guide her, including compression and Manual Lymphatic Drainage.

After hearing the diagnosis, Katie went to her car and cried from sheer relief that someone had finally believed her and discovered the root cause of her problem.

With an accurate diagnosis and a medical professional to help guide her, Katie started learning about lipedema and ways to manage it. Robin recommended a lipedema specialist, Dr. Boris Volshteyn at Atlantic Surgical Associates in New Jersey. Dr. Volshteyn and his team gave Katie lots of information.

She learned about compression therapy and the proper stockings to wear if you have lipedema. She started using a pneumatic pump, which entails two giant sleeves around the legs that manually push lymphatic buildup up to the top of the leg. Katie says it felt so good the next day that she felt like she had run a marathon!

"My legs feel lighter and more flexible now," she said. "I would recommend the pump to anyone, especially since manual massage is so costly and time consuming in the long term."

> *"Do not be discouraged because there is no cure. You can still experience big improvements in your quality of life!"* – **KATIE**

Katie also received a prescription for tirzepatide, a GLP-1 type medication, to reduce inflammation in her system. After two months of taking the medication, she says that her legs are smaller and she's lost about 15 pounds, mostly due to losing water weight. In addition to reducing inflammation, tirzepatide has also helped with her dietary preferences: "I find myself preferring a peach to a piece of pizza."

The three key parts of diagnosis are medical history, physical examination, and ruling out possible causes of symptoms. An exam includes visual inspection and physical palpation.

Connecting the dots

Now that Katie has a daily plan for managing her lipedema, she is going to try surgery, specifically lipedema-focused liposuction. She will undergo two to four surgeries with at least two months of recovery between each procedure.

According to Dr. Volshteyn, liposuction not only removes fat cells, but it also creates scar tissue between the skin and muscle structures, toughening up those connections—like an internal compression stocking.

The lipedema diagnosis and research helped Katie connect a lot of dots, between lipedema and a multitude of conditions that have concerned her throughout her life. For example, the arthritis in her knees was likely caused by the strain that lipedema was placing on her joints.

Because people with lipedema often have lymphatic and/or vein problems, once Katie has completed and recovered from the liposuction procedures, she will continue to get vein treatment for her venous disease.

"Venous insufficiency treatment has really reduced the swelling in my legs, and they feel less achy," said Katie. "It's also helped to eliminate the big stains that were on my legs."

Advice for others

For years Katie didn't have anyone to ask about her "giant" legs. Now she's her own advocate. After working with Robin and the Vein Healthcare Center, she connected with a lipedema specialist, then looped in her primary care physician who is "now fully on board." In fact, her PCP is the one who prescribed the tirzepatide.

*— **continued on page 17***

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Katie wants to share her story to help others who have lipedema, especially if they are just starting their journey or haven't been diagnosed yet. Here are some pearls of wisdom, in her own words:

"Living with off-handed, rude, or even mean comments all these years hasn't been easy. Since I was diagnosed, I haven't seen a therapist about it because of the cost. I did join a group of folks with lipedema on Tik Tok. You see people with the same stories that look exactly like you. There is a community out there!"

"If you opt for liposuction, go somewhere that has a team of people to guide you through the process, especially with insurance and documentation. Do extensive research and look for language that makes their practical support clear."

"Do NOT go see a regular plastic surgeon. Someone who doesn't specialize in lipedema could make the situation worse."

"If you can't get the surgery, there are still options for you. The pneumatic pump is such a great relief."

"Do not be discouraged because there is no cure. You can still experience big improvements in your quality of life!"

Finally, Katie has some advice for medical professionals: "Believe your patients. I was dismissed for thirty years. Everyone wanted to treat the symptom—in their eyes, the weight. No doctor ever tried to figure out the root cause." ■

PATIENT RESOURCES

The Lipedema Foundation
www.lipedema.org

The Lipedema Foundation is an excellent resource for patients and providers alike. Their mission is to define, diagnose, and develop treatments for lipedema through education and collaborative research.

Lipedema Simplified
lipedema-simplified.org

Lipedema Simplified provides global programs and resources to facilitate learning, connection, and belonging for women living with lipedema. Through empowerment and community support, they encourage women with lipedema to take proactive steps toward living their best lives.

Lipedema Project
lipedemaproject.org

Lipedema Project is the research division of Lipedema Simplified and provides research, resources, and expertise to individuals with lipedema and the providers who care for them.

The Fat Disorders Resource Society
fatdisorders.org

FDRS is dedicated to improving the quality of life for all people affected by adipose tissue disorders through research, education, advocacy, and collaboration.

FDRS's YouTube page shares videos from experts at medical conferences:
www.youtube.com/@FatDisordersResourceSociety/videos

Juzo Compression Guide
www.juzousa.com/Your-Health/Lipedema

Juzo USA has a helpful guide that explains how medical compression garments help with lipedema.

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More than half of the women in the U.S. have some form of venous disease.

Free patient information available in an interactive PDF format. To learn more, or to share with your patients online, go to:
www.veinhealthcare.com/earticle

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