

IS THIS RARE DISEASE Making You Look FAT?

Source: DermStore interviews Dr. David Amron about lipedema

At 10 years old, Lisa Marie Jones was urged by her physician to lose weight. So that's what she did: joined the swim team, met with counselors and nutritionists, kept a food journal, and tried just about every diet out there—all in the hopes of getting rid of unwanted fats in her buttocks and legs. Despite all her efforts, nothing worked.

"I noticed weight gain in my buttocks and legs, which was strange because I was eating less and exercising more," laments Lisa. "I had lost more than 120 pounds when I was 32, but I still looked extremely out of proportion since I only lost weight from my waist up. My upper arms, buttocks, and thighs up to my knees looked like they belonged to another person."

Contrary to what her doctor told her, Lisa wasn't obese. She suffers from lipedema, a rare and chronic disease that impacts 17 million women in the U.S. and 370 million women worldwide. This disease makes her accumulate fat cells in the lower half of her body, making her hips, buttocks and legs appear heavy, swollen, shapeless and disproportionate to her upper body. It can also be painful to touch, which is why it's also known as the Painful Fat Syndrome.

Lipedema vs. Obesity

Although lipedema was discovered in 1940, most physicians have not heard of the disease, so they end up misdiagnosing patients with obesity.

"Lipedema primarily occurs in the legs, specifically the anterior thighs, knees and ankles," explains Los Angeles-based dermatologic surgeon, Dr. David Amron. "It develops the appearance of tree-like, column-like legs with disproportionate fat storage and a lot of non-pitting edema, or excess swelling. Obesity is being overweight, and fat legs may just be a part of genetic disproportion, but with lipedema, there's also prominence of swelling, and again, that sort of column-like look to the leg."

Unlike obesity, lipedema occurs almost exclusively in women, and usually appears after puberty and progressively gets worse, even with medical treatments available to stabilize it. It also comes with increasing pain, heaviness, numbness, tenderness and bruising. But the major difference between obesity and lipedema? Lipedema is resistant to diet and exercise.

"If left untreated, lipedema will affect a person's mobility and quality of life, causing decreased ability to move easily. At later stages, it can even put a person in a wheelchair or possibly make them bedridden."

What Can Be Done

Lisa wasn't diagnosed until she was 36. But even though she felt some sort of relief knowing that her condition wasn't her fault, she also felt helpless. "My primary care physician told me there was no cure, and it was difficult to find a doctor in the United States who could help beyond conservative therapies," says Lisa.

Unfortunately, lipedema is a poorly understood disease—probably the reason most doctors are reluctant to offer medical relief. Among the treatments currently being offered is manual lymphatic drainage, a type of massage that uses gentle, rhythmic movements to stimulate the flow of lymph around blocked areas, balancing the body's fluid levels. Other healthcare providers offer medicines such as cimetidine and supplements such as selenium to reduce the inflammation and swelling. But according to Dr. Amron, all these treatments don't really seem to make a difference in the disease itself.

"I strongly believe that the tumescent lymphatic sparing liposuction is the best approach. There are several advantages to this approach. First, it's much safer and it doesn't damage the lymphatics. Second, it helps prepare the tissue by reducing the bleeding during the surgery and getting a much more pure removal of the fat. Lastly, it's very important in terms of patient positioning, which is vital to lipo-sculpture—especially with lipedema patients and these areas."

As in most liposuction surgeries, this procedure can last between an hour to two and a half hours, and cost about \$5,000 to \$9,000 depending on the severity. Typically, all problem areas can be treated in one to two surgeries, which can be scheduled as close as one week apart. Usually, the final results appear at 12 months, but most will be able to see 75% to 80% improvement at the six-month mark.

What Are the Risks

Asked why most surgeons refuse to perform this procedure, Dr. Amron says: "Lipedema is a complicated disease and it's still being understood. I think the reason most surgeons are reluctant to treat it with liposuction, which is the only real significant treatment for this condition and only real possible cure, is that these are very complicated areas we're dealing with—the calves, ankles and anterior thighs, areas that most surgeons who do liposuction tend to avoid, even in non-lipedema patients, because they are prone to irregularities. I think many surgeons are concerned with their ability to properly perform the surgery without damaging the deeper tissue."

While generally a safe procedure, all liposuction procedures carry a risk of bleeding, infection and scarring. In lipedema patients, the risk of long-term swelling can be greater, and has to be properly managed after the surgery with manual lymphatic drainage treatments and use of compression garments. Patients are also expected to do their part by keeping their weight down, maintaining a normal body weight and keeping their muscles toned.

As Lisa recovers from her first successful procedure and awaits her second one, she recalls what having lipedema feels like. "Lipedema is not only demoralizing, but also debilitating and painful. One of my biggest concerns was that someday I would no longer be able to walk because of it," she says. "Thankfully, the procedure was less than two hours long and it was painless. Within 24 hours of the procedure, the pain I experienced was alleviated with regular acetaminophen. I'm only three weeks post-op and still very swollen, but my thighs are an inch smaller in circumference and my knees don't hurt as much when I walk."

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