

BODY

A DEBILITATING DISEASE OF THE BODY'S FAT, LIPODEMA IS UNDER-RESEARCHED, UNDER-DIAGNOSED AND POORLY UNDERSTOOD. IT ALSO MOSTLY AFFECTS WOMEN, WHO FIND EACH OTHER ONLINE TO TRADE THE INFORMATION THEY AREN'T GETTING FROM DOCTORS.

OVER

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THE

BULLYING BEGAN AROUND the time Alyssa Wodabek hit puberty. She had suddenly started gaining weight in her legs and, no matter what she did, they just got heavier. It didn't take long before the kids at school noticed. "I felt like I had no control over my body—it just kept growing and I didn't know why," Wodabek says. "All I wanted was to fit in and wear the same clothes my friends were wearing. I don't know how many dressing rooms I cried in."

Her doctor suggested she go on the Bernstein diet to get the weight off fast so the bullying would stop. At 12 years old, Wodabek was restricted to what she now estimates to be around 700 calories a day: one apple for breakfast, two egg whites with Brussels sprouts for lunch, three ounces of fish with green beans for dinner. Wodabek visited the diet clinic in the morning before school, where she was weighed in front of everyone else in the waiting room. "You could always tell by the face of the nurse recording your weight whether it was going to be a positive meeting or not." When she didn't lose weight, her apple was taken away. "I remember feeling such shame. I felt like I was failing at everything I tried."

For the next five years, Wodabek bounced from one diet to the next and began working out twice a day. It didn't matter. Every time she looked in the mirror, she felt like she was inhabiting two different bodies: a size-six torso atop size-16 legs. And with the weight came pain. After training for months, a teenage Wodabek ran a 10K in Toronto in 2014, shedding tears behind her sunglasses as she neared the finish line because every step hurt, thanks to the "fireworks" in her legs.

When she was 18, Wodabek searched for answers on the internet and discovered a German study about a condition called lipedema. A disease typically triggered in puberty, it causes fat to build up in the lower half of the body and often in the arms as

well. She printed out 60 pages of information and took them straight to her doctor. At first, her doctor told Wodabek she was pronouncing it wrong. "It's *lymphedema*," she said. When Wodabek insisted, her doctor countered that lipedema wasn't real. Then she informed her that she just needed to lose more weight. "She shut me down so fast, I didn't know where to go from there," Wodabek says. She didn't see a doctor about her disease for another five years.

But lipedema *is* real. It's a condition that affects women almost exclusively. And it's not only patients like Wodabek who have struggled to convince the medical community that lipedema exists. Back in 2006, Dr. Karen Herbst, a Beverley Hills- and Tucson-based endocrinologist, felt like she was all alone, too. Desperate patients were coming to her for help, but any attempt to raise awareness—or even interest—among her colleagues failed. "When I first started talking about this, *nobody* believed me," she says. "They all thought I was a quack."

ALTHOUGH LIPEDEMA IS not a recent discovery, it does remain something of a mystery. First identified by two American doctors in 1940, it didn't garner much medical interest. Scientists still don't know what causes it or even how widespread it is: Some studies suggest five percent of women may be affected, but the condition is largely under-diagnosed. Lipedema is also under-researched, Herbst says, and the fact that it's a disease associated with women—like endometriosis and polycystic ovary syndrome—may be one reason why.

"We know that women have historically been ignored in research and that most studies are done on men or on male animals," Herbst adds. "I'm always saying, 'Well, what happened to the female mice?'" And, of course, women are still considered to be more emotional than warranted about our medical conditions—and are even blamed for them. "With lipedema, it becomes, 'You ate too much and didn't exercise enough so it's *your* fault. You did this to yourself, you made yourself obese.'"

Another barrier to our understanding of the disease is the medical community largely ignoring the importance of fat. "When I started out in my medical career, we thought that fat was just a storage depot

for triglycerides, or fatty acids,” Herbst says. “Then, we slowly began to see it as connective tissue made up of a variety of cells—including immune cells—and as an endocrine organ, which produces hormones. It’s actually an incredible organ and, if we understood it better, we would treat people with diseases of the fat better.” Herbst also notes that women have different fat than men, and more of it. For almost 20 years, she has worked to raise awareness about lipedema; in 2019, she headed up an NIH-sponsored conference to improve understanding and establish a standard of care for the disease in the United States, where none existed. Still, she says, there is a long way to go.

It’s not just the misshapeness of the body that’s a huge burden, Herbst says. The chronic pain and mobility issues in later stages of the condition, not to mention the social stigma of having an “imperfect” body, lead to anxiety and depression. “I often hear women say, ‘Well, I would go to the pool, but I can’t go out in public looking like this.’ That breaks my heart. Some days I just want to build a pool for women with lipedema and only women with lipedema. No one else can come.”

Herbst says that, in many cases, lipedema patients find better support and information about diagnosis and treatment from other women online, rather than from their doctors. In her 20s, Wodabek did just that, finally finding some answers in Facebook groups. “If it wasn’t for other women getting treatment and sharing resources, I don’t know if I would have been able to find the help I needed,” she says. “It really gave me hope to keep fighting.”

By this point, Wodabek’s lipedema was affecting her arms; she began to gain weight from shoulder to wrist. She was working in Toronto as a professional photographer and, during a long day of shooting, struggled to hold her camera steady. It was time to get help. Through a network of other lipedema patients, Wodabek found a doctor in Bronte, just west of Toronto, who was familiar with the disease. She was officially diagnosed in 2019, almost two decades after her symptoms first appeared.

ALTHOUGH YOU CAN’T prevent or cure lipedema, you *can* treat it. Managing the condition requires a holistic, multidisciplinary approach that ranges from conservative therapies to more invasive procedures. Conservative treatments include manual-therapy compression garments (to help reduce inflammation), physiotherapy, weight management and psychotherapy. For some patients, power-assisted or water-assisted (a.k.a. lymphatic-sparing) liposuction is an option. Both procedures dislodge fat from surrounding tissue and leave the

important lymphatics—the network of vessels and nodes that collect and transport fluid throughout the body—intact.

Wodabek discovered that it isn’t easy to find a surgeon who can perform the specialized procedure—plus, lipedema treatment is considered cosmetic and therefore isn’t covered by health insurance. (In 2018, a lipedema patient in Winnipeg had to remortgage her home so she could afford treatment after her attempts to get coverage were repeatedly denied by Manitoba Health. Breast reduction *is* covered, but treatment for a chronic, debilitating and potentially progressive disease is not.) Wodabek found one surgeon in Canada who offered water-assisted liposuction, but she couldn’t afford the \$33,000 price tag for each of the multiple surgeries required. Her Facebook groups recommended that she expand her search to Europe, where doctors have been treating patients for longer than in Canada and the United States (generally 20 years, compared to fewer than 10) and also tend to charge far less.

Wodabek’s research led her to Dr. Kai Klasmeyer, who has worked with lipedema patients for 13 years. Roughly 60 percent of his patients travel to his clinic in Cologne from outside Germany, and most of them find him via word of mouth. “We met over Skype and he was so kind, I immediately felt comfortable,” Wodabek says. Klasmeyer had a two-year wait-list, so she used that time to get in the best physical shape possible to ensure quick recovery post-surgery. Her first procedure was in March 2021 and covered the fronts her of thighs and hips. She returned to Cologne three more times over the next year, paying around \$7,000 each time, to tackle the backs of her thighs, her arms and her legs from knee to ankle.

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THREE COMMON LIPEDEMA MYTHS

“The recovery was pretty brutal. I was purple all over and couldn’t get off the couch; I needed help to do everything.” She also had to wriggle her way into custom compression garments, worn 24/7 for eight weeks, on her legs, arms and torso. “It’s like a second skin—once you’re in it, you’re in it.”

But Wodabek, now 32, is feeling at home in her body for the first time since she hit puberty. The fireworks in her legs diminished after her first procedure; she could climb stairs more easily and the swelling and bruising she’d endured for years went away. Right before her final surgery, she walked 14 kilometres exploring Cologne—with zero pain. “It’s life-changing. I feel as though someone took the sandbags off my legs. I said to my husband, ‘Is this how you always feel when you’re walking around?’”

Although there are no studies on the long-term effects of liposuction for lipedema patients, Klasmeyer says he has never seen a recurrence of the condition after surgery. “The longest study we have looks at patients after about 15 years, and it found very stable results,” he says. More importantly, he adds, patients need to be supported in managing their condition after their surgeries. A few years ago, he tried to work with a psychologist to offer more holistic post-operative care, but it was too complicated when so many of his patients were coming from other countries.

“Lipedema has a big impact on your entire life,” he says. Some patients aren’t able to work, and many suffer from debilitating depression and anxiety. Then there is the day-to-day management of the disease. Wodabek continues to wear her compression garments (\$800, not covered by OHIP) and sees her physiotherapist for manual lymphatic drainage about once a month to relieve any fluid buildup. Because there isn’t a ton of research on what happens next, patients are often just told to keep watching their diets, exercising and wearing compression garments to help keep the disease under control. Wodabek says that, after years of counting calories and obsessing over every meal, she is also still trying to make peace with food.

“Patients often continue to struggle with disordered eating, especially if it took them a long time to get properly diagnosed,” Klasmeyer says. “My biggest wish is for patients to have more streamlined medical support, so they don’t feel like they’re alone with their condition.”

Herbst says that support is on the horizon, although it isn’t happening yet. “It’s a complex disease but, finally, there are a lot of people working on it now,” she says. In 2019, Swiss researchers issued a call to action to raise awareness about lipedema within the medical community. In March of that same year, a European lipedema forum was held in Hamburg that involved experts from seven countries—everyone from surgeons and psychologists to physiotherapists and nutrition experts—all sharing information about the disease. Herbst herself is studying the work of doctors in other countries, including Spain and Brazil, to learn more about how anti-inflammatory treatments and diets may help patients manage lipedema. “We have to develop new ways to improve our care of patients, and people are doing that. It’s happening. And that’s very exciting to me.”

These days, Wodabek’s Instagram grid is a lively assortment of professional photos of beaming newlyweds, dreamy landscapes and artfully styled food interspersed with playful shots of her kind-eyed corgi, Nori. Naturally, there are selfies—it is Instagram, after all—but these are selfies with a purpose. Wodabek’s shots of herself, framed in a full-length mirror, are less of the “Hey, look at me!” variety and more of a “Hey, look what’s happening to me” vibe. She chronicles her experiences living with lipedema, sharing images of herself pre- and post-surgery (with confetti!), and she offers other patients encouragement and support. “We need more doctors to catch up and learn about this disease here in Canada. We need awareness and we need our medical system to support us,” she says. “I hope that by sharing my story, I can help raise that awareness—and help others who might be going through what I went through.” **BH**

LIPEDEMA = LYMPHEDEMA

Lymphedema is swelling, usually in an arm or leg but sometimes in the hands and feet, caused by a buildup of fluid when the lymphatic system becomes damaged or blocked. Lipedema, on the other hand, is a disease of the fat cells that causes fat to build up in the arms and legs. Lipedema can lead to lymphedema if so much fat accumulates that it blocks lymphatic vessels.

LIPEDEMA = CELLULITE

Both can cause dimpling of the skin, but cellulite is a cosmetic condition that occurs when collections of

fat push against the skin. Unlike the dimpling experienced by patients with lipedema, it isn’t painful or accompanied by swelling.

YOU CAN PREVENT LIPEDEMA THROUGH DIET AND EXERCISE

Studies show lipedema is genetic, passed down through other family members. “Everyone’s looking for the gene,” says endocrinologist Karen Herbst. “There is now a whole list of potential genes—most researchers think more than one is going to be responsible for creating lipedema tissue in the body.”