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CHRONIC DISEASE

LIPOSUCTION & LIPEDEMA

Cosmetic surgery becomes treatment of choice for those suffering from painful fat tissue disease

JEN RINI THE NEWS JOURNAL

Sameerah Al Khdhairi never thought twice about spending hours standing in front of a stove cooking bowls of biryani.

Now her time is spent sitting at home, crying and praying.

Al Khdairi, who grew up in Baghdad, Iraq, and now lives in Boston, Massachusetts, lost two sons and nearly a third to brutal violence in the Middle East. But on top of that pain, her health issues as of late have been worsening.

She has lipedema, a typically misdiagnosed chronic disease that affects how fatty tissue is distributed in the body. Often mistaken for obesity, as the condition progresses, fat continues to build up and can cause complications like scar tissue, infection, severe pain or lack of mobility.

Last week she traveled to Wilmington for treatment of the condition by one of the few doctors in the country who handle it, and she traded tears of frustration for ones of joy.

Liposuction, a cosmetic procedure performed worldwide to remove excess fat deposits, is now being adopted as a treatment to relieve the intense pain of lipedema.

Though patients speak highly of the benefits as it's gained popularity, it is often not covered by insurance and patients have to travel around the country to find a physician.

Only about 12 physicians perform the procedure specifically for the disorder, according to the Fat Disorders Research Society. Non-surgical measures such

See LIPEDEMA, Page 4E



PHOTOS BY SUCHAT PEDERSON/THE NEWS JOURNAL Local surgeon Dr. Nadiv Shapira (left), one of the few lipedema doctors in the country, gets ready to perform the procedure on Sameerah Al Khdhairi.



Sameerah Al Khdhairi has lipedema, a chronic disease characterized by fatty tissue excess and often swelling.

Lipedema

Continued from Page 1E

as compression therapy and massage can help, but lipedema cannot be managed with changes to diet or exercise regime.

"It's a huge burden," said Dr. Nadiv Shapira, a local



surgeon, one of the few lipedema doctors.

He executed the procedure for Al Khdairi pro bono, so she doesn't have to pay a penny. Since the procedure is typically considered "cosmetic," it is a battle to have it paid by insurance. Patients have to bank on spending anywhere between \$8,000 to \$12,000 out-of-pocket.

"It's not their fault," Shapira said. "It's not cosmetic. For them, it's a life-saver."

An outpatient surgical option not done in a hospital, the procedure takes about 12 hours including prep and post-operative dressing of the wounds. Patients are awake during the process but are numb to any pain.

Shapira favors a specific liposuction method called water-assisted liposuction, which uses less local anesthesia and fluid to remove the fat at a time. A pressurized stream of saline solution is used to break up the fat under the skin through small incisions, while a cannula, a thin tube, drains the fluid and fat from the area. The slow process minimizes damage to surrounding soft tissue and blood vessels and can be done on the legs, arms, buttocks and stomach.

About 3 to 5 liters of fat are extracted during the procedure, or 6 to 11 pounds.

"We don't rush," Shapira said as he examined Al Khdairi's legs last Monday before the actual procedure.

Major symptoms of lipedema include intense leg swelling that cause the legs to become enlarged from the ankles to the hips disproportionately from the rest of the body, and extreme tenderness, pain and bruising that makes it difficult for the patient to move.

There is no blood test to diagnose the condition, so doctors rely on physical signs and symptoms to guide treatment.

It is often mistaken for obesity or lymphedema, which occurs if there is a disruption to the body's lymphatic system. The system typically circulates lymph fluid to lymph nodes that filter waste and bacteria out of the body. Lymphedema often occurs with lipedema because the fat cells will block the lymphatic channels causing fluid to build up and additional swelling.

"It really gets worse and worse with time," Shapira said.

A 2011 study in the "Annals of Rehabilitation Medicine" says lipedema affects women almost exclusively, and 15 percent of patients had a family history of the disease. The cause is unknown, but clinicians suspect it is related to genetics or hormonal changes, such as from pregnancy or menopause.

After she gave birth to her last son, at age 33, Al Khdairi began noticing that her legs stayed swollen years after pregnancy.

She once had beautiful, defined legs, her husband and sister-in-law say. But over the last 20 years, they have developed into symmetrical columns, prompting Al Khdhairi to use a walker to get around. She winces in pain at a light touch to her calf.

"Now she can't do anything," said Awatif Albadri, Al Khdairi's sister-in-law, last Monday as they prepped for the procedure in Shapira's downtown Wilmington office.

Cathy Sampson's struggle with lipedema also began with swelling post-pregnancy that never went down. The former Zumba instructor was frustrated that as

PHOTOS BY SUCHAT PEDERSON/THE NEWS JOURNAL

Sameerah Al Khdhairi, an Iraqi refugee, gets a special liposuction procedure for a rare fat-cell condition called lipedema.



Only about 12 physicians perform the procedure specifically for lipedema, according to the Fat Disorders Research Society.



While Dr. Nadiv Shapira (left), performs the procedure on Sameerah Al Khdhairi her sister-in-law Awatif Al Badri, who helped translate, waits along the bedside.

her friends would work out and see results, she could never seem to lose weight and improve muscle definition.

"I always kind of accepted they (her legs) were fat," Sampson, 44, of Bel Air, Maryland, said. Over the course of 20 years her lipedema progressed to her buttocks, arms and stomach as well. A light touch to any part of her body felt as if someone was squeezing the skin and she could not walk or run in a straight line.

Sampson, however, just finished her last liposuction treatment with Shapira May 27. After some initial soreness, she said she is feeling less pain now that the excess fat and fluid have been drained and can actually see some triceps and biceps muscles.

After some back-and-forth with her insurance company, she said she only had to pay her \$3,100 deductible, while the insurer covered most of the procedure.

"I'll live a tight budget for that," she said. "I'm so happy. I don't regret anything. You feel better."

After a struggle to get to the United States, Al Khdairi is putting her health first.

"It's very little for what you went through," Shapira said to her of the pro bono surgery. "Let's hope it will help her."

At a check-up last Wednesday, Al Khdairi's stoic face relaxed and she easily broke into a smile. Though her legs are bandaged from her feet to over her knees and she still has to use her walker, she said she is hopeful and happy she will have some resolution.

"Thank you," she said softly.

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