

Surgery and therapy offer hope for patients with lymphedema

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Imagine an ailment that swells one of your legs to four times its size—one that destroys quality of life, bringing with it immense pain, even shame. For Salvador Castellanos, that nightmare was a reality.

"When I did go out, I couldn't wear pants," Castellanos said. "I would have to wear shorts. People would look at me in a weird way like, 'Don't get too close to this guy because he's going to give you what he has.' The hardest thing was not being able to take my kids to football and baseball practice. It would break my heart all the time. One day, I cried to God and asked him to send someone who would be able to help me."

After a challenging four-year journey, the father of three was eventually diagnosed with [lymphedema](#), an accumulation of fluid in the body that causes severe swelling. But thanks to a cutting-edge surgery being performed by Ketan Patel of the Keck School of Medicine of USC and the work of [occupational therapists](#) at the USC Chan Division of Occupational Science and Occupational Therapy, patients like Castellanos no longer have to suffer through this type of pain.

Lack of awareness

In his experience, Castellanos said there is an overall lack of awareness among physicians about lymphedema and those who do recognize the symptoms don't know how to help those afflicted by it, other than prescribing antibiotics for cellulitis—a common skin infection caused by

lymphedema—and sending them home. And that's what sets the occupational therapists at the Keck School of Medicine apart.

"There are a handful of us who are certified lymphedema therapists who took a specialty course to treat patients with this condition," said Michelle Hsia MA '08, OTD '09, assistant professor of clinical occupational therapy and manager of the department at the Keck School of Medicine.

"A lot of times, we'll get referrals from community hospitals, and the patient tells us, 'I've had swelling in my leg for five years and went from doctor to doctor and they just told me I was fat. Or they told me it will go away.' Sometimes they'll come on their own, not even knowing what lymphedema is, and say, 'Help me with my leg.'"

While Castellanos has primary lymphedema (occurring on its own), the ailment can also be a byproduct of chemotherapy, radiation or cancer-related surgery in which lymph nodes are removed or damaged.

About to give up

After being diagnosed with breast cancer in 2012, Sabrena Lee had a mastectomy and the removal of cancerous lymph nodes. Following radiation, she started noticing her affected arm was beginning to swell.

"I went to doctors and they would just give me a compression sleeve," Lee said. "I'm a hairstylist, so I was taking anti-inflammatories every night because my arm was in so much pain and so heavy. I didn't really want to go anywhere, so I stayed home. I had gotten to the point where I'd given up and was like, 'This is what my life is going to be.'"

Castellanos and Lee both found their way to the lymphedema clinic at Keck Hospital, where USC occupational therapists are devoted to

helping patients who are prepping to undergo surgery along with those who need to learn how to manage the lifelong ailment.

"In therapy, we do bandaging to bring down the swelling, massage, skin care education and exercise," Hsia said. "Lymphedema changes your skin to a tree-bark texture because over time there is so much fluid that there's no oxygen getting to the tissue." Manual lymphatic drainage is a type of massage that helps to open up the lymphatic system and push the fluid away. "Once the swelling is down, we give the patients some sort of compression that keeps them at that smallest size we've achieved," she explained.

Castellanos said the occupational therapists at USC taught him and his wife massage techniques and how to wrap his leg.

"They would explain everything in detail. My wife learned how to wrap it just as well as the therapists," he said. "So when we came home, she knew everything to do."

Educating patients

A lot of the pre-surgical work the occupational therapists do involves educating their patients about what to expect from surgery, but it also includes understanding how it will impact their everyday lives once they go home.

"We talk about how to change diapers, how to carry a 20-pound baby when you're not supposed to be lifting anything, sex and positioning, clothing, fatigue and exercise," Hsia said. "'How are you going to get into the bed? How are you going to bathe and get dressed? What are the things that are important for you to do independently?'"

After Lee completed a month and a half of therapy, Patel performed a

lymph node transfer surgery, a relatively new approach in which [lymph nodes](#) were taken from a healthy area in her body and placed in the limb affected by lymphedema to help drain fluid.

"I noticed a difference right away, and it gets better and better," Lee said. "The main thing I noticed was that I wasn't in pain."

Another option

A second option is a lymphovenous surgery, where pathways in the lymph and venous systems are reconnected to improve flow.

"At the end of treatment, I've had patients say, 'I don't have any pain in my arm,'" Hsia said. "'Now it doesn't wake me up in the middle of the night.' That makes a huge difference. They still have to wear a compression sleeve and manage the lymphedema, but they say, 'I will take this over what I was experiencing before any day.'"

Castellanos is currently undergoing pre-surgical testing and is hoping to schedule lymph node transfer this summer. He said the therapy program has changed his life.

"I just went to one of my son's baseball tournaments and got to see him play baseball for the first time," he said with a big smile. "Now I feel much better going out. I put on a pair of sweatpants the other day and was like, 'Wow, you can't even tell my leg is swollen.' I know there is a long road ahead of me, but I'm really happy with the outcome of everything."

Provided by University of Southern California

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