

Life after lymphedema

Changing and developing practices are inspiring hope for the future

By Andrew Matta

Life after lymphedema...was scary, intense, I felt alienated and trapped. Most of all; it was a never-ending replay of what happened the day it came into my life. I've replayed the whole 24 hours of the day I woke up with lymphedema, October 18, 2007. What caused it? Was it something I ate? Was it an injury that caused it? Was I born with this? Was this inevitable? Could I have prevented this? These questions have resonated with me until now.

The truth is, lymphedema sucks. The truth is, I wouldn't wish lymphedema on my worst enemy. The truth is, I refused to believe I'd be stuck with this condition forever.



Wearing compression socks for the first five years of my diagnosis of primary lymphedema was awful. It made me feel different from everyone around me. It felt like I was 'handicapped.' Mind you, I was 20 years old, had just started college, and the world was starting to open up in my eyes... and then, lymphedema entered my life. Being



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around my friends, my classmates, and my colleagues felt different. I felt completely alienated from everyone around me; for some reason, lymphedema took control over my life. Everywhere I'd go and anything I wanted to do, this "thing" would be in the way. I started organizing my days - whether it was school, studying, going out, or going to church—around my lymphedema, and frankly, it was beating me down.

One morning, five years after being diagnosed, I woke up in a total panic mode—my foot was inflamed, infected and painful. As a result, I wasn't able to walk on my left leg for about six months. This is where the toughest thought came to mind: Would I be able to walk again? Is this going to go away? Am I going to get better? I started thinking to myself at that point: no compression socks, no flow therapy, no laser massage, no lymph drainage can get me to walk at this point. That led me to my next thought: surgery.

I sought out surgery around the world, in countries including Japan, United States, Finland, England, and finally, Italy. After a long road, I chose surgery in the small town of Genoa, Italy. Doctor Corradino Campisi, a Professor of Vascular and Lymphatic Surgery, would operate on me on July 16, 2012, with his unique, one-of-a-kind technique of lymphovenicular anastomoses surgery.

Now, I didn't know what to expect. I mean, flying out to a foreign city, getting surgery on my lymphatics—by someone who, for all I know could have been a fraud—was very

nerve-racking. But I guess being nervous was the start of something incredible. It has been almost four years into my long-term recovery, and I must say lymphedema, now, doesn't take control over my life as it did before. How have I noticed my lymphedema getting better? Well, the grade of compression and the frequency (how many days or how long per day) I wear my compression socks have dropped - drastically. My foot feels terrific; it feels healthy, it feels reliable. But not yet perfect.

There may be no direct 'cure' for lymphedema. There may be no exact method to immediately reverse lymphedema. That's fine. But what I can say is this: there's definitely hope. Much more hope than we had 20 years, 15 years, 10 years, or even five years ago. Research is evolving, and medical technology is advancing, so we can't continue to view lymphedema treatment now the way we did decades ago.

The fact is: wearing compression socks, manually draining lymphatics, undergoing compression therapy, getting my leg wrapped and bandaged, taking antibiotics, resting and elevating the limb....all *managed* my lymphedema. But placing new lymphatics that bypass the damaged/blocked lymph nodes—allowing the lymphatic fluid to flow at ease—this *treated* my lymphedema. And for that, I am forever thankful.

I can't bear the thought that there are more than 140 million people in the world who are suffering a lot worse than I am.... and for that I applaud you all. You are overlooked heroes. I urge you all to keep up the heroics, keep up the strength, and most of all, don't lose hope. **LP**

