

5 stages of my lymphedema journey

By Nancy Tvarok



I was diagnosed with breast cancer in 2003. I had a mastectomy, chemotherapy and radiation. Cancer...gone! Within six months of the end of my treatment, swelling started in my left arm. I was diagnosed with secondary left arm lymphedema. That is where my journey with lymphedema began, in stages that went something like this.

Stage I

I do NOT have a clue!

Lymphedema was not going stop me. I was on a mission to “get back to normal”. Within three months of my lymphedema diagnosis I had TRAM

(transverse rectus abdominis) flap breast reconstruction surgery. I thought the lymphedema would go away. I did not want to listen to my physical therapists.

They had done a good job explaining my condition, showing me how to compression wrap, and giving me incredible massages. But every time I went for treatment, I just stared at the poster of the lymphedema man in the treatment room. It appeared to me that I have more than enough lymph glands to take care of all my swelling needs. Total denial on my part.



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Stage II

I’m going to beat this thing. Or get more edema in the process...

I joined clinical trials. I increased my strength and reduced my swelling through the PAL (Physical Activity and Lymphedema) study. I also spent 30 days visiting a hyperbaric chamber for 90 minute “dives” (like a sea hunt adventure without the dolphins). That didn’t fix anything but I now do have two things in common with Michael Jackson. We both wore one glove and hung out in hyperbaric chambers! Unfortunately I picked up trunk edema along the way. My body was prime for more swelling. This was extremely frustrating for me. Out go the pretty bras and in come the heavy duty ones. Finding a good bra that gives you style, comfort and compression is like the search for the Holy Grail. I have a drawer full of experiments that have various degrees of success. The perfect bra for trunk edema has not been created yet!

Stage III

Okay I guess I better get used to the lymphedema thingy

What am I supposed to do again? I call this getting very friendly with your physical therapist. Going for therapy three times a week, applying kinesio tape, wrapping your chest every night, wearing your compression glove and sleeve every day and being the perfect patient/pupil.

Stage IV

If I’m doing everything right, why can’t I be cured? AKA—pity party

I can accept getting breast cancer but I’m really unhappy that the treatment that cured me also gave me arm and trunk lymphedema. Stage IV comes and goes. The pity party lasts anywhere from a few minutes up to a day. Then I just get tired of hearing myself whine and I get on with my life.

Stage V

Acceptance

This is hard for me. I am a perfectionist and do everything with the expectation that I will be successful. Perfection to me is no more lymphedema – but that is not going to happen. Lymphedema has taught me that acceptance does not mean failure. Acceptance means treating my mind and body kindly; staying healthy, wearing my compression garment, wrapping at night, stretching and exercising. I also stay connected to a fabulous physical therapist who understands my condition. We are a team and she keeps me motivated to do my best. 📌

YOUR THOUGHTS

If you would like to share your story and advice with others, contact us via email:

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