

Lymph Story

One patient's journey with head and neck lymphedema inspires courage and perseverance when faced with life's unique challenges.

By Willa Condy Seymour

In 2009, I started wearing compression garments on my head. It took three years of wearing the garments, but my head swelling improved and the circumference decreased by two inches. I am blessed that my husband has good medical coverage and I was finally able to get a night time compression garment.

I only found out in 2012 that I had primary full body lymphedema. By then, I had swelling not only on the left side of my face, but also in both arms, one leg and in my torso. It was not news anyone wants to receive. That same year, I attended a lymphedema awareness day, organized by the BC Lymphedema Association. It was both wonderful and frustrating at the same time. I got to talk with experts and fellow patients, which was an invaluable experience. The frustration

She encouraged me to use exercise and compression garments for my legs.

was realizing how treatment and support for lymphedema is lacking in BC for those who have primary or secondary lymphedema from any surgery other than breast cancer.

I am grateful for the advice and help I have received on this journey. On two separate occasions, I ended up visiting Ottawa, and met with an amazing lymphedema



Willa Condy Seymour is 58 years old, has experienced facial swelling for eight years and in the past five years was diagnosed with full body lymphedema. A member of the BCLA, Willa thanks her husband, family, friends, doctors and therapists for her positive outlook and continued quest to learn how to help herself manage the lymphedema.

“My advice to anyone dealing with lymph issues is—remember to laugh.”

therapist during each visit. She encouraged me to using exercise and compression garments for my legs. She also recommended that I exercise in the pool and I now swim three times per week. I sleep in night time garments, both for my head and my arms. I practise self-massage, and use a low intensity light laser to help me cope. I also have lymphatic massage twice a week. Last year, I managed to lose 40 pounds, which helped take some pressure off my lymphatic system. This past April, I also started acupuncture treatments. It helped me get through the summer.

Lymphedema makes waking up in the morning interesting, as I never know what the day will bring. My facial lymphedema has crossed quadrants and the right side of my face has now started swelling as well. During the day, I never know whether I'll end up looking like Dolly Parton, or Beyoncé in

the booty! I view lymphedema as a dragon: any time I relax and goof off I get flamed! I try to inform and educate others about lymphedema. When I travel, I don my “bank robber mask” and my best earrings. I explain why I am wearing compression garments and then hear them tell me about their sister, cousin or friend that is dealing with lymph issues. Even though I don't wear my facial garment on a daily basis anymore, I still talk about lymphedema. I explain what I have and what I am doing to manage it.

Knowledge is power. When I have a bad night I find myself using the internet to find answers or to check out what strides are being made in treatment options. I belong to Facebook support groups and a support group in my area.

My advice to anyone dealing with lymph issues is—remember to laugh. Remember that it is your body—not your doctor's or your therapist's. They are very important in helping to deal with lymphedema, but we, the patient need to be in charge. Also remember—sometimes we have to cry. Lymphedema can change our body but it can't touch our souls! Keep looking out and stay involved in life. [LP](#)