

My Personal Story of Growing Up with Lymphedema

By Charlene Hewitt from Victoria, BC



I was born and raised in Jamaica and in 1986 at 11 years of age was diagnosed with primary lymphedema. That particular summer, I went with my family on holiday and while at the beach I got stung by a jelly fish. In a short time I had a large welt from my inner thigh down to my ankle. It was an angry shade of red and fooled the physician who examined me into thinking I had deep vein thrombosis. I was quickly rushed to hospital where it was confirmed that I had cellulitis. By then, my ankle and lower leg had begun to swell and the physician suspected that I had lymphedema. I was hospitalized for two weeks and treated with high doses of antibiotics in order to control the infection.

After I was released from hospital, my doctor gave us the grave news that lymphedema was incurable and that I would just have to learn to live with it. He went on to say that it is likely that I had this condition because of the way in which my lymphatic system was formed. He recommended that I wear a compression garment and elevate the limb at night. However, as a very self-conscious teen, I did not want to be caught dead in those unattractive stockings. As for elevating, I shared my

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dorm with seven other girls at an all-girls boarding school and the last thing I wanted to do was stand out.

My teen years were made all the more difficult because I had to deal with a disease that no one around me understood. My leg continued to worsen and I was hospitalized again at 14 years old for two weeks because of another bout of cellulitis. After this, my leg increased in size and my toes started to resemble the famous little sausages that lymphedema sufferers are so familiar with. I began to elevate my legs at night and this seemed to help, however briefly.

The most significant challenge in living with lymphedema is the emotional toll it takes on you. As you can imagine, it was even more painful to deal with this illness

while facing the emotional roller coaster that is adolescence. My parents did their best, but for eight months out of every year I lived with other teenage girls who were sometimes harsh. Hardly a day would go by in school when I was not upset about having to deal with lymphedema.

Now, I should probably tell you that this condition also affects my 101 year-old grandmother, father and aunt. We strongly suspect that my great grandmother may have also had it.

After being diagnosed with lymphedema, I quickly found out that there was little or no information. I searched the internet in 1995 and discovered the National Lymphedema Network based in the US. I attended their conference in 1996 and then went to Florida for my first intensive MLD treatment in 1997.

It was not until my second intensive MLD treatment in 2006 that I became more compliant with compression. I started bandaging more regularly at night and I now wear my compression garments every day.

I participated in the Pittsburg University Lymphedema Family Study about 6 years ago and I was humbled to be part of that exciting development in lymphedema research. I can hardly wait until they find the root cause of this debilitating disease. I was also very encouraged to learn about the BC Lymphedema Association. Instead of becoming wrapped up (pun intended) in my own struggles with this condition, I now find myself willing to volunteer and get involved with helping others to help themselves. [LP](#)

