Life with lymphedema

By Maria Atherton

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My journey with lymphedema began in October 2010. After being diagnosed with Triple Negative, Invasive Ductal Carcinoma, Stage II – Grade 3, the second most aggressive form of Breast Cancer, on September 17, 2010, I had the first of what would be a total of three surgeries, beginning with a lumpectomy with axillary lymph node dissection. I had 18 axillary lymph nodes removed that day; two of which tested positive for cancer.

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My lymphedema grew worse. One month post-chemo, my surgeon booked my second surgery to further clear the margins of where the tumor had been. After my first surgery and again after the second, I experienced post-operative infections, which resulted in very low white blood cell counts and high fevers that required rounds of antibiotics to resolve; all of which affected and worsened my lymphedema.

The pathology came back from the margin surgery and showed the cancer had survived chemo. On June 1, 2011 I had my third surgery to fully remove my left breast and some of the surrounding muscle tissue against my chest wall. I did not know at that point how much worse lymphedema could get until I began aggressive radiation therapy at the beginning of July 2011 to the middle of August 2011, every day, Monday to Friday, for six weeks. Radiation therapy sealed the deal with my lymphedema. I live with chronic swelling, peripheral neuropathy, and constant pain, despite Manual Decongestive Therapy (MDT), compression garment and the use of a Lympha-Press pump; my quality of life and level of physical ability have been drastically and permanently affected.

I also live with the recurrence of a rare condition called Sweet's Syndrome. Sweet's Syndrome — also known as acute febrile neutrophilic dermatosis — is a rare skin condition marked by rapid onset, increase in swelling, fever and painful skin lesions that appear mainly on my left arm from shoulder to finger tips.

My motivation for joining the BCLA first as a member and then, as their Vice President, is to bring a greater awareness of the effects of lymphedema on quality of life to a broader audience of oncologists, patients, medical practitioners, medical researchers, and government officials. There is a need for greater supportive care for patients with primary and secondary lymphedema. At this point, in British Columbia, supportive care for lymphedema patients is nearly non-existent. There is a strong belief amongst oncologists and physicians that there "is no evidence based proof medically, that any method of treatment for lymphedema is effective for long-term improvement." This statement alone strengthens my objective to promote greater research and the implementation of knowledgeable and effective supportive care. LP

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Maria Atherton is the BCLA Vice-President and a breast cancer survivor living with lymphedema. She works part time as a Special Education Assistant. Her volunteer experience, grant writing and fundraising skills are a welcome asset to the BCLA. She is married with three daughters ages 13, 11 and 10.