

Patience is a virtue

A story of how lymphedema transformed a family's lives

By Debbie Ciotti-Bowman



My journey with lymphedema began in 2007 when I experienced the diagnosis of Stage 3 metastatic melanoma of my calf requiring the removal of the entire inguinal basin of lymph nodes draining my left leg. Thus began a transformation in my life and that of my family's, leading to some interesting experiences....



Debbie Ciotti-Bowman and daughter Catharine Bowman.

Issues with leg swelling cropped up quickly; I experienced congestion and a painful lymphangitis on the inside of my thigh near my knee. I later developed foot swelling and another painful lymphangitis over the top of my foot/lower calf. This was an eye-opener, as I had always been in good health! Interestingly, to this day, after those first bouts of lymphangitis, my foot remains swollen to varying degrees, and the area at the inside of my thigh just above



Debbie Ciotti-Bowman is a retired nurse from Hamilton, Ontario and a current board member of the Lymphedema Association of Ontario. She wishes to see improved provincial health coverage for the management of lymphedema, and hopes for significant treatment developments that will make the physical regimes required for lymphedema care easier.

the knee will be the first painful area when I'm having a "bad day" with my lymphedema or am on the verge of contracting cellulitis.

Trying to find the help that could administer and teach me the required physical treatment to manage the lymphedema was quite a challenge. I couldn't believe that in 2008, the only type of treatment to stay well with lymphedema was either hard to find within my region, or was not covered by insurance or affordable to me on a regular basis!

I'm incredibly grateful for a physiotherapist who opened a not-for-profit, "Cancer Rehab" clinic (Hamilton, Ontario) for two afternoons per week, staffed by physiotherapists and a kinesiologist. These health care professionals were concerned with cancer patient rehabilitation, including teaching the "basics" of lymphedema management, as they too recognized the scarcity of regional lymphedema resources and lack of government financial support for lymphedema treatment. In 2008, this was a warm and welcoming haven where we all learned about recovery, adapting to our new situations and supporting each other! Unfortunately this clinic closed after only 4.5 years in operation. The necessity of compression stockings and bandaging became clear, and I experienced the benefits

of a prescribed exercise program combined with compression bandaging of my leg.

It was around this time that my 9-year-old daughter Catharine Bowman, started to say things to me each day like, "Mommy I love you and some day I am going to cure you," often moving me to tears with the intensity of her expression...

Time has now passed, and I have learned that to manage my lymphedema I must:



- ✓ **Wear compression stockings every day of my life** (summers are hot), and a waist high, night leg garment every night (always hot). There are times that my leg acts as the "barometer of my life"!
- ✓ **Not wait "a day or so" to see if the red patch on my leg will clear up on its own** (a mistake that makes me very sick the next day), but **get the benefits of starting my cellulitis antibiotics right away** (an unforgettable "aha" moment!)



✔ **Wrap my leg with compression**

bandages and exercise with a program that is designed with physiotherapy and kinesiologist assistance. This combination balances the increased blood flow to the leg muscles with the ability of my leg lymph circulation to remove new lymph accumulation from the leg. Over a long period, the optimal order of exercises has been worked out.

✔ **Balance daily movement of my legs with periods of lying flat**

to relieve gravity's effects of congestion on my lymphedema leg. Caring for this leg is time consuming, but it's the way to maintain leg comfort and manage the lymphedema.

✔ **Keep my muscles healthy**, and breathe deeply to keep lymph circulation going.


✔ **Avoid certain foods**, such as excess salt and anything that contains "bad fats" to avoid increased leg congestion and lower abdominal swelling.

✔ **Consistently take care of my leg and myself**, so that I remain able to carry out the physical management and movement required to care for my leg in the future, when I'm older!

Gradually, I've found the therapy assistance I need, and am blessed with some wonderful contacts and an extremely loving family.

A very meaningful segment of our family's journey with this condition has been watching our daughter develop into a compassionate, caring science researcher and lymphedema advocate. I am astounded every day by the way Catharine overcame her worry as a sensitive youngster watching me adapt, and transformed it into a positive energy combining her love of science with her deep desire to tackle a huge question such as: "Is there a pharmacological treatment or even a cure for lymphedema?" As a teenager she's poured her heart into developing her own research proposals, searching for funding and promoting lymphedema awareness. She has been encouraged and supported by Dr. Pierre-Yves von der Weid of the University of Calgary and by another senior scientist at Hamilton's McMaster University as she carries out molecular research investigating the possibilities of pharmacological assistance for this chronic condition. She recently had the opportunity to discuss her work with Dr. Stanley Rockson at the BC Awareness Day in Vancouver, who also encouraged her to continue to pursue her particular path of research inquiry.

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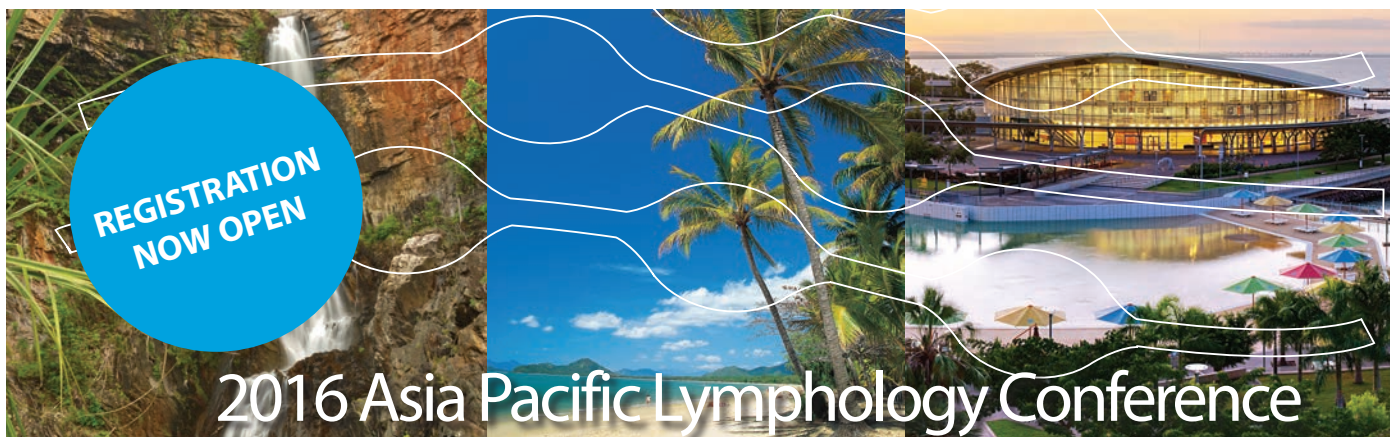
So, it's been an interesting journey while I've dealt with the challenges of a life-long condition and the family has taken up new journeys or ways of looking at things. I think we've all learned that "sometimes the things we can't change, end up changing us"—for the better! 

YOUR THOUGHTS

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