Self-care for lymphedema

A patient’s journey with lymphedema led to acknowledgement of the condition by the Quebec government

By Rachel Pritzker

My pre-cancer and pre-lymphedema life included a happy home, kids and grandkids, an exciting career with an international airline. I was looking forward to an early retirement in order to start a new career.

Instead, in 1998, cancer struck! At that point things started spiralling out of control. I was diagnosed with malignant melanoma. After a struggle with metastatic melanoma for the next two years, including surgeries, radiation therapy, debilitating treatments, several recurrences, and finally a one-year participation in a clinical trial, I had a miraculous recovery despite all odds.

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I survived cancer, yet was left with a strong reminder: lymphedema of the leg that emerged immediately after my first surgery and never left. In fact, when I woke up from surgery, none of the health professionals who treated me were able to tell me why my left leg was 35% larger than the right. I kept hearing that swelling after surgery is common, and that it would disappear. But it never did.

At that point, I started to do some research on the Internet. That is where I first saw the word lymphedema, and realized, “that is what I have.” A year after I had started treatment for melanoma, I finally met Dr. Anna Towers, who referred me for treatment to one of only three therapists certified in lymphedema in Quebec at the time (for a population of 7 million).

By that time, my lymphedema had worsened and prevented me from going back to work and participating in my regular activities. The impact of lymphedema on my daily life was overwhelming: the necessity to rush each morning to put on my compression garment, not always well-fitting and at times painful; the impossibility of finding shoes to wear over my swollen foot or pants to fit my leg; the inability to sit or stand for long periods and more. As the Quebec government did not recognize lymphedema, my intense treatment and maintenance became financial and emotional burdens.

In 1999, while I was still in cancer treatment, it was time to share all the information that I had gathered about lymphedema with others. The first education and support meeting, with Dr. Towers as speaker, was advertised through flyers in hospitals and clinics, as well as on TV and radio. Thirty people attended. That evening, when I listened to the questions and stories of some of the people attending our first meeting, I knew that this was just a beginning! It was a meaningful evening for many people in that room, some having believed that they were the only ones that had this condition that doctors could not diagnose, and finally having a name for it: lymphedema!

The audience represented the mixed population of Quebec: different ages, races, and languages. What they had in common was a non-diagnosed swelling in the arm, leg, and neck—and they all went home with the hope that maybe now they could find a solution to their problem.

I devoted the next weeks and months to building what later became the basis of the Lymphedema Association of Quebec (LAQ). With the help of four patients, we made plans for our next monthly meetings, and prepared pamphlets that included all the information we could find on the Internet about lymphedema. In October 1999, the Lymphedema Association of Québec was founded as a non-profit charitable organization.

For the next few years, I struggled to keep my swelling under control, it was challenging. The years of cancer treatment and disability due to lymphedema caused me to give up my job of 25 years, and left me without work and no health insurance. Treatments and garments were out of my budget. Then,

Rachel Pritzker is the founder and president of the Lymphedema Association of Quebec, a patient-based non-profit charitable organization. Under Rachel’s leadership and dedicated volunteers; patients, therapists and health professionals have brought the association to the forefront of lymphedema advocacy, awareness and education programs in Quebec.

the unimaginable happened: a therapist introduced me to a new philosophy of life, self-management. Through self-management, I was able to bring about the most important changes in my life and my health habits.

The first step, and the most challenging one for me, was learning how to bandage my own leg. Step by step, I improved my techniques of applying multi-layer bandages. Self-measuring helped me know exactly how I am doing in terms of controlling the swelling. I was in charge of my own compression, right at home, day or night. I tried some alternative compression garments, and chose those that worked best for me. However, the self-bandaging remains the basic tool that I always go back to.

The second step: exercise. I selected physical exercises that would help reduce my swelling, but also bring me joy and spiritual wellness, and began my own program: dragon boating, Qigong, walking, and a gym with a special program for my needs. Aqua Lymphatic Therapy exercises also helped me to improve my self-massaging techniques.

Other components that I adhere to are skin care, proper nutrition and weight control. The self-management program that I started over a decade ago has become a crucial part of my healing, as much a part of my daily care as brushing my teeth. At the LAQ, we have also focused our education and support programs on using all tools available to succeed in self-care.

Today, there are many patients receiving lymphedema care and training for self-management, thanks to the more than 100 certified therapists across Quebec. And to our joy, the Quebec Ministry of Health now recognizes lymphedema and partly covers compression garments. All this is thanks to the hard work and support of volunteer patients, health professionals and industry that support the LAQ and its cause.

Affiliate Profile

Lymphedema Association of Quebec
Association québecoise du lymphœdème

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Lymphedema Association of Quebec

Established in 1999, The Lymphedema Association of Québec (LAQ) provides support, education and awareness to people living with lymphedema, their families, and friends and to healthcare professionals. We inform and educate about lymphedema and its causes, risk reduction and treatments of this chronic disease, and encourage scientific research leading to a cure.

LAQ's objectives:

- provide support to persons afflicted with lymphedema;
- defend and promote the interests of persons afflicted with lymphedema;
- provide education and awareness to persons afflicted with lymphedema, their families and healthcare professionals, about the causes, treatments and prevention of this chronic medical condition and establish an information center for this purpose;
- encourage scientific research for a cure for lymphedema.

We are proud of our accomplishments:

- LAQ is the primary organization in Quebec to offer support and education to people living with lymphedema.
- Our monthly group meetings cover topics from basic lymphedema information, to self-management, risk reduction, exercise and more
- Health professionals wishing to certify as lymphedema therapists have benefited from special training courses organized by the LAQ
- Health professionals throughout the province turn to us for information and guidance about a condition that continues to be poorly understood
- Our bi-lingual website offers a wealth of pertinent up-to-date information
- Our Telephone Support Program has volunteer therapists responding to phone and e-mail enquiries from the public
- Our bilingual education pamphlets and resource guides are used by health professionals and patients throughout the province
- Our joint education program with the McGill University Research Program offers lectures on lymphedema risk-reduction and therapy to nurses and therapists in hospitals and clinics
- LAQ's annual conferences provide known speakers and exciting workshops to hundreds of attendees from across North America

On January 1, 2014, our activities of defending and promoting the interests of persons afflicted with lymphedema resulted in the recognition of lymphedema by Québec's health ministry, and the partial reimbursement of compression garments and bandages.

In order to fund all of these activities, LAQ has relied on the generous support of our members, sponsors, and donors, as well as on fund-raising activities such as the annual walk for lymphedema, awareness and bazaars days and more.

We wish to thank all the volunteers—persons living with lymphedema, therapists, suppliers and friends – who help us to attain our goals.