Living with Lymphedema

By Kathleen McManus

I was first diagnosed with lower body lymphedema in the fall of 2007, shortly after completing my cancer treatment. I recognized the symptoms early and sought a diagnosis and implemented the usual management strategies such as compression, Manual Lymphatic Drainage (MLD), skin care protocols and exercise.

Exercise has always been an important part of my life. It has proven to be an effective aid to controlling the swelling and improving my emotional well-being. In addition to puttering in my small city garden, I put mileage on my hiking boots. Every morning, often before dawn in the winter, the dog and I take a two-hour walk in the park, or on the beach. I truly delight in learning to identify the various waterfowl that pass through our city, in getting a glimpse of a fox, a tiny mink, a snowy owl, or a beaver by the pond's edge.

I was introduced early to the Lebed Method (a therapeutic exercise program specifically designed for breast cancer patients), which I still use for warm-up and cool-down. However, as I needed to improve muscle strength, I started light weight training. Exercise, the use of a compression sleeve, and MLD returned my thigh to normal dimensions. Nevertheless, I did also learn to be moderate, because increasing the leg weights too rapidly brought on tendinitis, and a renewed bout of swelling. MLD and rest aided my recovery.

Despite my successful management, cellulitis has proven to be my primary challenge. I suffered the first bout in November 2008. I thought I was coming down with the flu when nothing would relieve me of the bone-chilling cold. My temperature neared 40°C. By morning the worst of the fever had subsided but I noticed a faint, blotchy red rash on my legs. Cellulitis was never discussed during my cancer treatment. I remembered something from a National Lymphedema Network (NLN) pamphlet, acquired at my first Lymphedema Association of Ontario (LAO) conference, and I headed to Emergency.

At the 2011 LAO conference, I learned that cellulitis can also occur because of a bump rather than a clear skin break. The British Lymphology Society, *Consensus Document on the Management of Cellulitis in Lymphoedema*, helped me understand my own situation, since each of my four more recent bouts have been different. In the first two bouts, symptoms were mild with the fever setting in after the rash. Physicians had some difficulty assuring themselves that I had cellulitis and not a fungal infection, in spite of my history. From bitter experience, I know many family physicians are unable to diagnose skin conditions properly. The next two bouts were far more intense. In both cases, I was given hospital care and assigned a home-care nurse to attend to intravenous (IV) antibiotics. I have been taking an antibiotic daily for the past year and started a lower dose at the six-month mark. I will see where things stand at my next appointment later this month.

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I now also travel with a two-week supply of antibiotics but still run the risk of requiring out-of-country medical help which would not be covered by my insurance company–due to my pre-existing condition.

Nevertheless, with support from an excellent MLD therapist, a garment fitter, and information provided through organizations like the LAO, the Canadian Lymphedema Framework (CLF) and the International Lymphoedema Framework (ILF), I live a relatively normal, active life. I am able to do much of what I enjoy in spite of the challenges that lymphedema and its side effects present.

Kathleen McManus and her husband live in Toronto with two cats and a dog. They also have two young adult daughters. Kathleen is a member of the Lymphedema Association of Ontario and has kindly supported them with volunteer time.

TELL YOUR STORY

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