

# Lymphedema affects more than the patient

## A spouse's perspective

By Michael Holloway

I think if you asked anyone in a relationship with someone who has lymphedema (LE), they would tell you that the disease has not only affected their partner; it has also impacted them in a number of ways.

My wife, Lynn, developed secondary LE in her left leg as a result of surgery for a large cancerous tumor in her left groin, back in 2003. Although her surgeon told us that LE would be a side effect of this life-saving surgery, we had no idea what we were in for!

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Having cancer twice had already changed Lynn. She was a vibrant person who now lived in fear of recurrence. This last surgery, considered palliative, had left her feeling like her days were numbered, which scared me too. Dealing with lymphedema was now an added burden on her body, mind and spirit and what affects her, also affects me.

As she spent the first year of her recovery trying to learn about lymphedema, I felt helpless. I watched her struggle emotionally as her leg grew in size and her mobility became challenged. She searched the internet to try and figure out what she was supposed to do, as her medical team was not at all helpful. She knew she had to get a compression

garment and spent months with the fitter getting things wrong time after time - all the while, her leg was growing larger.

Although the medical community considers Lynn morbidly obese, my girl has always had style. Just before I met her, she was a model and clothing designer in the plus-size market. Now her lymphedema no longer allowed her to wear the clothing and shoes she loved. As her self-worth lessened, I felt her withdrawing, and our intimacy as a couple suffered.

Our life changed for the better when we found a massage therapist trained in MLD/CDT. Finally, Lynn had found someone who knew something about lymphedema! The therapist taught me how to bandage Lynn's leg, as Lynn was unable to do this on her own. We also found a good person to assist with fitting her compression garments and I learned to help her don her garment each day, another thing she is unable to do on her own. Although we are thankful I am able to assist, Lynn yearns for her independence.

Just when we were thinking we had this lymphedema thing licked, along came bouts of cellulitis to throw more challenges at us. These infections require IV antibiotics for a week or so, and we have the added bonus of Lynn having terrible veins. So, not only does she have to endure the infection in a



hospital setting, but she must have a PICC line inserted which usually has to stay in for a number of weeks to ensure the infection is completely gone.

There have been many difficult times with cellulitis over the years, and we have been fortunate to now avoid hospital visits by starting oral antibiotics at home. Each time she gets sick, Lynn pleads with me to not take her to the hospital. I know that if we don't see early signs of the infection abating, I will have to be the "bad guy" and take her to the emergency room.

With each bout of cellulitis, Lynn tries to figure out what had she been doing in the past week that might have brought it on. Things she has enjoyed doing in the past



have been crossed off her list for fear of creating the perfect environment for an infection to start. I love to get away camping, but after getting an infection a couple days after being at one of our favorite spots, Lynn is now unwilling to

do that activity. I wanted to do some travelling to tropical climates over the past few years and have had to plan to go alone or with friends, as the heat is too much for her with the compression stocking. Most summers, she keeps indoors as much as possible to stave off getting too hot. For me, I stay in a job that I no longer enjoy, just to be able to have extended health care to help with some of our expenses related to lymphedema.

I am glad to have my wife still with me and hope we have many more years together. Lymphedema has changed our life. I wish for her and the thousands of other Canadians living with this disease that more will be done in the future to assist them. **LE**



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