

# The quest to live *with* lymphedema and *not* for lymphedema

By Angela Connell-Furi

Living with lymphedema definitely has its challenges. Having full body primary lymphedema and multiple chronic illnesses puts me into an entire different ball game.

By the time I was six weeks old, I already weighed twenty pounds. The doctor's only response was "what are you feeding this kid?" My mother's response was "breast milk". As an infant and into my teens the swelling in my limbs was thought to be related to Type 1 juvenile diabetes. The swelling progressed immensely in my feet and legs. By the time I was twenty one years old, I was given the universal reply "lose a little weight, it will go away". My diagnosis took several years. It was a podiatrist who suspected that I had primary lymphedema and referred me to a vascular surgeon who had taken an interest in lymphedema. I was so grateful for the ray of hope that could lead me to find answers to why my legs and feet were so swollen. By 2009, my lymphedema was progressing in my arms, face and stomach as well.

Since my diagnosis I have been blessed to have the opportunity to attend the Foeldi Clinic in Germany twice with my husband accompanying me. There he learned how to do full body MLD. We were quite persistent in learning as much as we could. We enjoyed getting out of the clinic and walking in the Black Forest with our walking poles! Everybody

is different, but for me it was ideal to get two hours of exercise daily. I absolutely love the flat-knit compression garments I was provided. They have been so wonderful and helpful in my lymphedema management (along with CDT of course). I have a garment for my toes, knee-high stockings, a Bermuda short which goes from mid calf to under my breasts, arm sleeves and gloves. I cannot wear all garments at once as the compression is too much for my heart to handle. So I wear my leg garments during all waking hours as gravity can be so cruel. I wear my arm garments at night sometimes (as recommended by Professor Foeldi) and I wear them during exercises (when my arms are in use).

My worst lymphedema now is in my stomach. I really struggle with that because it's progressing quite fast although I'm doing everything I can. I was told by Professor Foeldi to lay down three times a day and do deep breathing exercises as that's really important for stomach swelling. I have asked my specialists here in Saskatoon and in Germany if debulking surgery would be right for me, but the responses have been that it is much too risky for me.



**Angela Connell-Furi** lives in Saskatoon and worked as a Continuing Care Aide before her multiple health issues became too restrictive. She is now focusing her love of helping others within the lymphedema community. She is a member of the Lymphedema Association of Saskatchewan (LAS) Board, and takes care of their website, Facebook and Email communications.



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Lymphedema has impacted my life in several ways. Based on my current medical conditions, I feel the most grief over the inability to continue working in my career (Home Health Aide for the Saskatoon Health Region) and my inability to have children. My husband and I wanted to proceed with further fertility procedures, however, in consultation with a high risk pregnancy physician, we were advised to discontinue because of high mortality risk due to my multiple chronic illnesses including Type 1 diabetes and full body lymphedema. We have been on the list for adoption in Saskatchewan for almost eight years now. It took six years to have our home study done, and we continue to wait.

My greatest blessings in life are my husband, family, and friends as they have been super supportive throughout the years!



Photo: Angela Connell/Fur

Everyday tasks that we take for granted like chopping food, standing and sitting for long periods of time, holding a book, using a hair straightener, kneeling, and even walking can be a hurdle for me. Summer time is different for me, as with thick garments and the heat, I rash easily and my entire body swells; I must say I do love Saskatchewan winters! I miss many things, especially roller blading and ice skating. There is so much time involved in managing four limbs with lymphedema along with the rest of my body. A very big challenge is my immune system, as when I get a flu or cold I have a very hard time fighting it off. A cold can last six

months. The Foeldi Clinic's motto is "live with lymphedema not for lymphedema". I still have not figured how to do this yet as lymphedema truly does impact everything I do.

Despite the losses that I grieve there are many things to be thankful for. My greatest blessings in life are my husband, family, and friends as they have been super supportive throughout the years! I could not handle every day management of lymphedema without my husband Trevor. He does full body MLD on me when we can find the time, as he is working two jobs. Trevor also assists me with bandaging my legs and I must say he does it better than I

ever could. I try to concentrate on the positive things in life and regardless how challenging living with lymphedema can be, I still have much to be grateful for.

I have met so many wonderful people through sharing my story and fighting for better lymphedema care throughout Saskatchewan. Lymphedema patients from all over the world have contacted me after reading my story on the Lymphedema Association of Saskatchewan (LAS) web site. This makes me feel like I'm a part of helping others and that helps me to cope with things much better. I'm on the LAS Board and really enjoy the volunteer work I do. My biggest achievement with the group would be the web site I put together (with the assistance of a web designer). I strongly advise patients to get involved with their provincial associations, as it can be therapeutic! For more details on my story please visit [www.sasklymph.ca](http://www.sasklymph.ca).

**Be positive, take care and never give up!** 📌



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