Taking lymphedema seriously

Learning fun ways to manage your condition could lead to new hobbies

Who knew the ukulele could be the cherry on top of a polished routine?

By Gail Reichert

I have lymphedema as a result of breast cancer surgery in 2011. Today, I am a little over seven years out from treatments and two years past the completion of my estrogen blocker. Like that of many other cancer survivors and lymphedema patients, my journey has had its share of ups and downs, frustrations and successes. This journey initially required a lot of questioning, searching, self-advocacy and patience in order to find out what I needed to do with the swelling in my arm two months after my double mastectomy and three weeks after moving to the Sunshine Coast in British Columbia from Calgary.

I knew the exact moment that my lymphedema started as I had been presented with do's and dont's from breast cancer educators in Calgary on how to avoid lymphedema. Despite being armed with that knowledge, I decided to move a small, empty hutch six inches by myself. I believe this triggered the lymphedema in my left arm. Living in a small rural community at the time presented a great deal of difficulty in getting a proper diagnosis and assistance to deal with it. Within two months I had exhausted my available resources on the coast and the physiotherapist advised me to get fitted with a compression garment in Vancouver, as my arm was not responding to the pneumatic pump treatment. Fortunately, during my garment fitting session it emerged that the fitter knew a doctor in Vancouver, Dr. Elliott Weiss, who treats lymphedema patients. Armed with that bit of information, I finally felt like someone was responding to my many pleas for help.

Initially, although I was receiving wonderful treatment from Dr. Weiss and his staff, I was in self-denial and naïve about the impact lymphedema can have on your life and your future if you decide not to take the doctor up on his advice or choose not to actively work at reducing the swelling. Eventually though, Dr. Weiss got through to me and from then on I determined that I needed to be vigilant and proactive. I was going to tackle this condition with every bit of knowledge and assistance that was presented to me. I joined the BC Lymphedema Association, read *Pathways* from cover to cover the moment I received it, went to a Lymphedema Awareness Day, took part in a couple of research studies pertaining to lymphedema and found a physiotherapist and a massage therapist, who were trained in Complete Decongestive Therapy (CDT) and Manual Lymphatic Drainage (MLD). They helped me contain and reduce the swelling. I also worked with my own GP to help him come to understand lymphedema better by sharing my knowledge, *Pathways* magazines and what I was doing in the research groups to stay on top of the lymphedema.

A second move (2016) to another small community on south Vancouver Island had an even more detrimental impact on my lymphedema. The loss of all my support and the stress of building a new house while trying to find my stride in a new community resulted in me neglecting my lymphedema for a little over a year.

At the beginning of 2018, my arm had grown to such a size that it was beginning to interfere with clothing choices. I was experiencing a burning sensation regularly, as well as debilitating breath-snatching muscle spasms in my left mastectomy scar almost daily. The neglect of the previous year and half was manifesting itself. It was the wake-up call I needed. This *Pathways* magazine was again a great resource in finding an amazing Registered Massage Therapist (RMT) with many years of practical experience dealing with lymphedema patients. She not only provides therapy but she also helped me connect with a breast cancer

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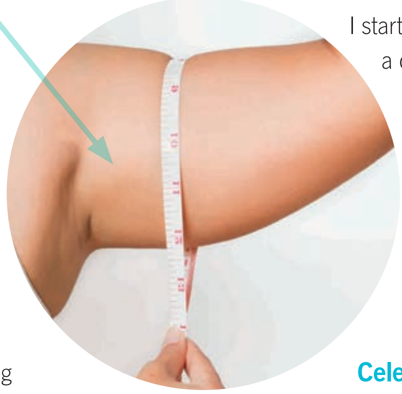
survivors' exercise group. She informed me that based on the fibrotic tissue texture of my arm (the skin was thickening and hardening, and the difference in size relative to my other arm), I was likely in an advanced secondary stage of lymphedema and that I should confirm this with a physician. I had no clue that it was at that point and it scared me quite a bit.

I started seeing both a lymphedema therapist and scar tissue release therapist once a month, and I also engaged in a regular stretching program at home using DVDs (whose instructor is a breast cancer survivor who knows about lymphedema). I discovered dry brushing and try to do it before each shower that I have. I can feel the lymph move in my arm after I do it and my skin is much softer now too. I also increased the use of my night-time compression so that I now wear it every night.

Editor's Note:
If you wish to try dry-brushing as part of a self-lymphatic drainage routine, please ensure that the bristles are extremely soft. You don't want any micro-abrasions to your skin. Also, please be aware that if you feel a tingling sensation afterwards it may not be so much due to enhanced lymph drainage but rather to stimulated or irritated nerve endings. Too much tingling is probably not a good thing!

I have been recording my arm measurements using a MyoTape since taking part in a research study at University of BC (UBC). I diligently recorded my measurements right after removing my night compression and about an hour after waking. As a result of the two treatments per month, some weight loss (about 10 pounds) and the other efforts I made, between January and June, the circumference of my arm reduced in size – anywhere from – .3 cm to 2 cm, depending on the area of my arm.

My RMT said that the fibrotic tissue in my arm was loosening up, as did the scar release therapist. Unfortunately, I had to reduce the frequency of treatments about this time due to my extended health plan benefits being exhausted.



I started playing the ukulele regularly sometime mid to late October. By then, treatments with both therapists had once again reduced in frequency to one treatment from either one of them every 6 to 8 weeks. However, after I started playing ukulele I began noticing something happening with my arm. (I play for anywhere from 5 – 30 minutes at a time about five days a week). I felt it was helping to move the lymph a bit. I mentioned this to both therapists, and they confirmed that it made sense, as I am using the fingers in my left arm (lymphedema arm) to make the chords on the frets as I play songs. Using the fingers like that requires the muscles in my arm to be contracting and moving too, which could conceivably result in the lymph being moved. I decided to measure my arm in December to see if what I was observing was proving to be true. I discovered that what I was observing was happening to a greater degree than I even anticipated.

Every measurement has gone down, except for the 10 cm mark. It may be that I didn't tighten the night-time compression garment enough the previous evening or I read it incorrectly. The most significant decrease is in the upper arm; the area that has been the most troublesome to reduce with the night time compression because anytime you wrap an arm you start with the garment or wrap the tightest at the wrist and loosen off as you get closer to the armpit. My measurements now resemble measurements on that arm when I was 20 or more pounds lighter. Playing the ukulele is now an additional tool in my toolbox for reducing the volume and size of the arm, and it's a fun way to do it. The sleeves of my clothes are fitting much looser as a result... no need for the seamstress to make the sleeves fit better!

Another thing I do to stay active is that I started playing pickle ball a couple times a week in November. I don't believe it is significantly impacting the measurement as my left arm is down by my side for much of the time I am doing pickle ball, but I enjoy it all the same.

Celebration time

I most recently I returned from another lymphedema session with my massage therapist. She was duly impressed with the condition of my arm! All the expense this past year of therapy and incorporating new activities into my life have been worth it. My arm is noticeably smaller, the fibrotic tissue is softening, and I once again have some mottled coloration on my upper arm. The area around my elbow is still swollen and my forearm is still fibrotic (though both areas are smaller in size), but the therapist said that continued treatments, compression, diet changes, and increased physical activity will all pay off in the end. As fibrotic tissue continues to soften in my upper arm it will allow the lymphatic fluid to flow more readily and I should see more softening of the fibrotic tissue lower down the arm and a reduction in volume. Who knew adding ukulele and pickle ball to my life would be so beneficial plus fun?