

Compliance supports good surgical results

By Linda Gimbel

In April 2013, I had an Inguinal Node Dissection at the Tom Baker Hospital (Calgary, Alberta) for Stage III Melanoma. After 18 lymph nodes were removed from the groin area the surgeon warned I might be at risk of developing lymphedema. Shortly after the surgery, I noticed swelling in my right leg and I have been living with lymphedema in that leg ever since. Even though I was compliant with exercise and wearing compression day and night, my lymphedema progressed. I was aware that excess weight could aggravate lymphedema so I began to follow a low carb/high fat way of eating and successfully lost 35 pounds. I definitely saw an improvement in my condition, but I wasn't satisfied. In 2016, I received a referral to see Calgary-based surgeon Dr. James Kennedy and finally was scheduled for Suction Assisted Protein Lipectomy (SAPL) surgery on July 22, 2019. I was pretty excited!



July 16/19



July 29/19



Linda Gimbel is a Cancer Survivor. She has been living with lower limb lymphedema as a result of an Inguinal Node Dissection in 2013 for Stage III Melanoma. Linda lives in Stettler, Alberta and often travels over 6,500 km in a year to attend appointments in Calgary and Red Deer.

My home in Stettler is a three-hour drive from Calgary. To cut down on travel time for the surgery and follow up appointments, my husband and I decided to park our RV for a week at a lovely campground in High River, an easy 30-minute drive from Calgary. Post surgery, I was fortunate to have very little discomfort and was going for walks the following day. I attended the Lymphedema Clinic at the Holy Cross Center (Calgary) for three compression bandage changes before returning to Stettler. This was followed by two appointments for compression wrapping at the Cancer Clinic in Red Deer, a final appointment with my lymphedema therapist at the Holy Cross Center, a fitting for a new compression stocking and then a final checkup with Dr. Kennedy. I was aware these appointments were necessary and I knew I had to be compliant if I wanted to see good results.

This procedure was very successful in size reduction. Prior to surgery, my right



leg (from the upper thigh to the ankle) was significantly larger. I found it necessary to buy slacks two sizes larger and then take them in at the waist and left leg to accommodate this size difference. Since surgery, I am able to buy clothes in my true size with no alterations! This has been such a great improvement for me both physically and mentally. The incisions healed in about three weeks but in total, my leg was wrapped for about five weeks. Once I received my new compression stocking, I felt like a million bucks!

I was now able to resume the activities that I love and know are so good for me. I try to attend aquasize and deep water jogging classes at the swimming pool three to four days per week. This is the very best activity for my leg lymphedema. I also returned to weekly yoga classes and recently was fortunate to learn of a program called EXCEL (Exercise for Cancer to Enhance Living Well) which I have attended twice per week via Zoom since January of this year. I enjoy regular walks with my husband, Lloyd, and dog, Bear, as well as working in the garden and flowerbeds. During summer, I may occasionally be found on the golf course and in September I will look forward to a five-day golf trip with a group of ladies, our 30th annual.

Many things can aggravate my lymphedema, such as too much standing or

sitting, kneeling on the right leg, exercise that is too strenuous, or sitting in a certain chair; often I'm not even sure what the cause is. I like to be active but find it necessary to make time in the day to rest and elevate my leg, either in a recliner or on the floor with my legs up the wall. I find evening is the best time to practice self-care such as using my pump and performing manual lymphatic drainage.

Since retiring from a career with the Alberta Government in 2013, I realize that taking care of my health and lymphedema has become my new full time job. I have very supportive family and friends and I also feel very fortunate to have been able to access so much information and help through provincial and national lymphedema organizations. I would encourage other lymphedema patients to advocate for themselves and do as much research as possible. As lymphedema patients we must take care of ourselves and follow the advice of our medical team and therapists.

I have been very pleased with the results of my procedure and would highly recommend it to other patients. 

Suction Assisted Protein Lipectomy (SAPL) lymphedema surgery is a procedure that can effectively remove the excess solids that have accumulated in chronic lymphedema. In many patients, these lymphedema solids build up over time and cause an arm or leg to no longer be reducible to a normal size with conservative therapy.

Project EXCEL is EXercise for Cancer to Enhance Living Well, and provides an exercise and behavior change program to those living with cancer in rural and remote cities & towns across Canada. EXCEL currently offers most of its programs online via the zoom platform. They hope to resume some in-person programs when safe to do so. In the meantime, there are exercise programs on their YouTube channel as well as an "at-home downloadable pdf workout plan".

Patients interested in learning more or joining their programs can reach out via email (wellnesslab@ucalgary.ca) and check the website: <https://kinesiology.ucalgary.ca/labs/health-and-wellness/resources/resources-patients>



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Getting hopeful

The ideal lymphatic surgery candidate's attitude

By Anne-Marie Joncas

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My life with lymphedema began in October 2015, during my last chemotherapy treatment for breast cancer. My left arm suddenly swelled and pain set in; a pain I have always described as a pressure that burned continuously, day and night. My doctors told me that lymphedema does not hurt. They tried a medication for neuropathy, but it didn't help. The burning sensation was omnipresent even though the overall volume difference in my arm went from 16% to 5% in intensive therapy. Over the next three years, it varied between 7% and 14% (as I was taking Tamoxifen). Despite my 24/7 adherence to a well-fitting compression garment, my therapists' care, my practice of self-management and my aqualymphatic routine, the pain was still there. It interfered with my life and messed with my spirit.

My arm reacted strongly to heat, to physical activity, to immobility, to the slightest change. It was difficult to cook, because one foot away from a boiling pot, my arm would swell. When I walked on a treadmill, my arm would swell and burn even more. Earning a living became difficult because my arm was a burden for computer work. I could no longer go out when the weather was humid and over 24° C. I was isolated at home with air conditioning. I was seriously depressed.



Anne-Marie Joncas is inspired by the resilience of people living with lymphedema, putting her energy and ideas to work for the Lymphedema Association of Quebec (LAQ). She has been the LAQ Executive Director since February 2019.

Defining my goals

In 2017, I brought my wish list to Dr. Marie-Pascale Tremblay-Champagne, a surgeon at Maisonneuve-Rosemont Hospital. I would like to: have less pain, lead a more normal life and slow down the degeneration of the condition. Having attended support groups, I noticed that lymphedema veterans talk about the evolution of their disease, despite their vigilance and good care. I wonder if tissue aging alone is to blame, or if tissue deteriorates more quickly while bathed in lymph—an important question when you intend to survive cancer forever.

My surgeon was surprised by the absence of a classic expectation on my list: saying goodbye to compression garments. But I wanted to reduce the pain so much that I was willing to continue wearing compression.

A clear picture

My surgeon ordered imagery to visualize the damage and especially to identify the healthy lymphatic vessels that can be reconnected. She injected indocyanine green between my fingers (ouch!) For the very first time, I could see the inside of my arm. Relief: nothing was broken in my hand. The swelling there was only reflux. Revelation: there were white lines and a leaking pool on my forearm, an area that splashed everywhere upon touching it. Worry:



Author's hand 24 hours post surgery.

Do I still wear my compression 24/7? Yes and it is not a problem for me. Will my arm age better? Only time will tell. But I now know that the future is much brighter.

there was a black area at the top of my arm. That's because there were only one or two vessels still functioning. Most importantly, my surgeon saw the possibilities for reconnection. She then spoke those magical words, "You can have lymphatic surgery knowing that your lymphedema will not be worsened by the procedure and can be improved with an impact that is unknown for now." I decided to take my chance, to entrust myself to her care and to temper my expectations.

Staying realistic

Thanks to the imaging, I now have a better understanding of my lymphedema and I have hope. A realistic hope, because I understand that lymphatic surgery does not cure lymphedema. It can improve symptoms, sometimes to the point of greatly improving quality of life. I will have to continue to take care of myself through self-management, including exercise, healthy weight, self-drainage, skin care and possibly wearing compression. I also understood that my arm would be improved in terms of drainage and volume, but that there was no promise for pain reduction.

D-day

On May 27, 2019, I finally entered the operating room to try to repair this painful and heavy arm. With her fairy fingers, my surgeon, who is experi-

enced in specific lymphedema procedures, surrounded by her team and relying on a powerful microscope, spent seven hours reconnecting my healthy lymphatics to my veins. The principle is that the lymph is diverted to a functional “pipeline” instead of leaking through the damaged lymphatic network. As soon as I woke up and the nausea was over, I got to go home.

Recovery

The five lymphatic-venous anastomoses performed in three separate sites on my arm were less invasive than a dental root canal. During recovery, the operated limb usually swelled beyond pre-operative measurements. I endured the swelling and remained in elevation for five days with Coban bandages on my arm, but nothing on my fingers. Then, the swelling was reduced with Coban, while I resumed my activities and decongestion exercises. Three weeks post-op, measurements were taken for a new sleeve to wear from week five. Since it takes one year for the volume to stabilize at its lowest, I budgeted to change my sleeve every two to three months.

In retrospect, I can say that my self-manage-

ment skills and adherence to a well-fitting compression allowed me to recover quickly. Not to mention that access to my pool six weeks after surgery and for the entire summer afterwards allowed me to get down to below my pre-operative measurements in only eight weeks.

Rewarding results

Before the operation, the difference in volume between my arms was 14.61%. Two months after surgery, it was down to 4.62% and 10 months after surgery it was down to 0.59%. In September 2020, after a summer in the pool, my affected arm was 0.5% smaller than my healthy arm! Is there less pain? Yes! In this respect, lymphatic surgery has transformed my life. In fact, I only feel that old burning pressure if I do something crazy like carrying a 50 lb. bag of dirt by myself in the middle of a heat wave. I like to hypothesize that my tissues, less overwhelmed by lymph, might be less exposed to inflammation.

Do I lead a more normal life now? Yes! I can go outside in hot weather and despite humidity. I work and cook as I wish, I garden,



I go Nordic walking, and I ride a bike without pain or discomfort. I can spend hours with my friends on a sunny terrace. I have an active and satisfying life. Do I still wear my compression 24/7? Yes and it is not a problem for me. Will my arm age better? Only time will tell. But I now know that the future is much brighter. **LP**



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