

Canada's Lymphedema Magazine

Pathways

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FALL 2020



Lipedema: A paradigm shift

Remedial
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As much as we still don't know about lymphedema, the medical community falls even further behind in understanding lipedema. This disease that affects primarily women and is associated with disproportional fat distribution of the legs, along with fat tissue pain and tenderness, has been commonly misunderstood. Dr. Tobias Bertsch sees over 1,500 patients a year in the Foeldi Clinic in Germany. His 15 years of clinical experience led him to challenge the traditional view of lipedema. The resulting 5-part publication on the "Myths of Lipedema" and the new European Consensus on Best Practices for Lipedema have contributed to an essential paradigm shift in the diagnosis and treatment of lipedema. Pamela Hodgson of our Editorial Board and myself had an opportunity to interview Dr. Bertsch via a fascinating and animated Zoom call in June. We plan to have a subsequent article describing in more depth the new directions for treatment.

Our wonderful cover photograph is not a stock photo of a model—but that of Christa Klein, a woman living with lipedema in the Netherlands. Her story is part of a great book entitled "Impressed by You" and published by the Netherlands Lymphedema Network. You can read her story and find out how to buy the book on the *Pathways* references section on the CLF website.

Dr. Kathleen Francis provides us with a great article that not only articulates well lymphatic anatomy and physiology but also provides a strong foundation for better understanding

treatment protocols. Although retired now from her physician practice, she remains an educator with a lymphedema school in the USA. We thank her for submitting this article, during COVID at her remote cabin in the Minnesota woods.

The two-page pullout for practical decongestive exercises for arm lymphedema (Winter 2020 issue) received positive feedback from our readers. Marize Ibrahim and Angela Yung, two physiotherapists in Montreal, generously agreed to create the leg version. If you are living with leg lymphedema, you are encouraged to post this article on your fridge and make these exercises part of your daily management regime.

Lymphedema not only affects the physical body, but impacts the quality of life for patients as well. Dr. Vaughan Keeley and his team developed a widely recognized tool for measuring quality of life in lymphedema. Thanks to Katie Riches and Vaughan for their contribution describing the process of development. We look forward to the imminent publication of their QoL instrument for breast lymphedema.

I've been asked why I've never shared my personal story with readers. We receive great article submissions from across the country and so not to upstage these stories, my own article always seemed to get deferred. However, I realized at the International Lymphoedema Framework conference last year in Chicago—that many people, who I've known for years, did not even know I had lymphedema! My

background might help you understand my passion for lymphedema education and moving patient care forward. I encourage all people living with lymphedema to continue to send in their stories as well.

During this COVID time we distributed our Summer 2020 issue via complimentary online access, as a way of giving back to the community. With our North American and international connections, we reached more than 35,000 additional readers around the world. These numbers demonstrate how strongly connected the international lymphedema community really is. The CLF is proud to be part of that wonderful supportive community. We thank everyone for "passing it forward".

We are excited to announce a reciprocal agreement with the *Journal of Lymphoedema* (JOL), which will increase worldwide distribution of each other's publications. Discussions with similar organizations are also well underway. This is just one of the strategies the Canadian Lymphedema Framework is developing to grow the *Pathways* readership and subscriber base.

Constant improvement for the magazine is paramount. Our last reader survey was in 2017 and we are eager to hear again about your preferences, your reading habits, what is important to you and what articles and authors you want to see featured in *Pathways*. We encourage you to submit your feedback by participating in a short online survey by going to www.canadalymph.ca.



Anna Kennedy

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Pathways
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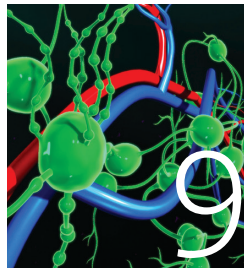
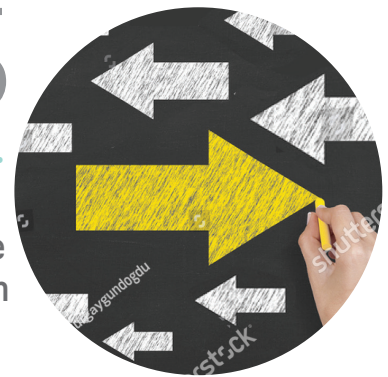
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Lipedema – A new paradigm shift

An interview with Dr. Tobias Bertsch

In discussion with Anna Kennedy and Pamela Hodgson

Q How would you define lipedema today?

According to the European Lipedema Consensus, two main criteria define lipedema: the first is the disproportional fat distribution of the legs (and sometimes of the arms), and the second is the complaints arising from this fat tissue like pain, heaviness, tenderness—that are essential for the diagnosis of lipedema. In other words; to diagnose lipedema, it is not enough if the patient is just suffering from bigger legs.

Women's legs are a tricky topic. It's a tricky issue. I see far more women that come with a diagnosis of lipedema from their doctor. Yet when I examine them, their legs are completely healthy, even though they might not have what society considers as “top model legs”. Lipedema is not only big legs, otherwise every woman who is not happy with her legs would say that she has lipedema, and as a consequence want to have Manual Lymphatic Drainage (MLD) or liposuction (at least this is the situation in many European countries where MLD is paid for).

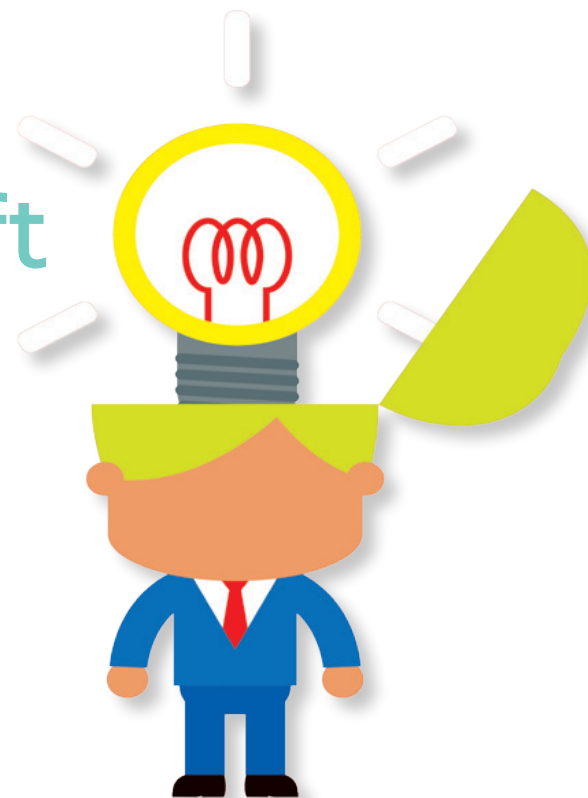
At my lipedema lecture at the 2018 International Lymphoedema conference in Rotterdam, there were around 300 women—mainly doctors and therapists (no patients). I asked the audience “Who among you is happy with your legs?” I saw only five hand signals from approximately 300. That speaks volumes. For this reason, we need the second criterion,

the complaints. The other issues the huge majority of patients with lipedema are suffering from and that the European lipedema expert group felt were essential were: weight gain and obesity, and psychological issues. Both criterion have to be considered in regards to proper diagnosis and therapy of the patients.

Q Tell us how the European Lipedema Forum came to be.

Who are the key players and what was the process of consensus?

In the last few years, the number of lipedema patients was increasing notably. They came into the out-patient clinic and told me their legs are swollen, that they suffer from edema; that they gain weight because of lipedema. At the same time, patients were focused on getting MLD (which is covered by insurance in Germany) and more and more they were focused on liposuction. From my perspective, patients suffered first and foremost from pain in the soft tissue and weight gain as well as mental challenges, like eating disorders, depression, and chronic stress. They suffered from a lack of self-acceptance because of the current beauty ideal in society. So I started to challenge the traditional view of lipedema. I started to lecture about this topic in 2014 and also started to write in 2018 the series of articles “Lipedema; myths and facts”, together with my wonderful colleague, psychologist Gabriele Erbacher. I had positive



I started to challenge the traditional view of lipedema, lecturing and writing about the myths and facts.

feedback from many medical doctors. However, there was also negative feedback, particularly from doctors who perform liposuction and from patient support groups, who were not happy that I was challenging MLD and liposuction as helpful therapies for lipedema. As a consequence, I invited European experts (Kristiana Gordon, Denise Hardy, Robert Damstra, Ad Hendrickx, Christine Moffatt, Tobias Hirsch, and many other European recognized experts in this field) to discuss the topic of lipedema in a forum. The first meeting was in 2018 and the second in 2019.

Those invited had either written about lipedema or were on commissions with organized guidelines within their country or were on the board of a society. All of them were treating lipedema patients on a regular basis—that was essential. We used the Open Space concept, suggested by Christine Moffatt, with a professional moderator team leading



Dr. Tobias Bertsch is a senior consultant at the Foeldi Clinic in Hinterzarten, Germany, specializing in lymphology and bariatric medicine. In 2008, Dr. Bertsch developed a unique, multi-disciplinary therapy program for patients with morbid obesity, obesity-associated lymphedema, and lipedema. Dr. Bertsch is the leading author of the article series “Lipoedema - myths and facts.” He organized the European Lipoedema Forum that created a Consensus and Best Practice Document on Lipoedema, published in 2020.

the meetings. The result was the European Consensus, which is published in part 5 of the article series about lipedema (see references).

Q Can you help us understand what the key myths are and how they have been challenged by your group?

MYTH 1: Lipedema is a progressive disorder.

Its obesity and weight gain that is progressive. Many patients come scared that lipedema is progressive. They see pictures of severely obese women and they read a lot of misinformation from some lipedema websites. As a result, they are afraid they will end up like many of these obese women. In actual fact at the Foeldi Clinic, every day we see patients with lipedema who present a completely stable lipedema over many years because their weight remains stable. Every patient at the Foeldi clinic gets weighed and measurements are taken of the stomach and legs. We have measurements spanning 20 years and we see these patients are completely stable.

Isabel Forner-Cordero from Spain, conducted a study, which she presented last year at the International Society of Lymphology (ISL) in Buenos Aires. All patients in her study who could stabilize their weight could also stabilize the volume of their legs. Only those who gained weight experienced an increase in their leg volumes. By the way, there is no pathophysiology, no scientific concept, which could explain why, and how lipedema should

be progressive. Not at all. This is really good news for our patients; they should know that lipedema is not progressive, that lipedema will be stable—if their weight remains stable.

MYTH 2: Lipedema causes mental illness.

The psychologist at the Foeldi clinic published two studies, the last one, published in September 2020 followed 150 patients^{1,2}. According to these studies 80% of lipedema patients suffered from mental issues like eating disorders, post-traumatic-stress-disorder, depression, chronic stress, burnout and others. The huge majority of them had these mental problems before the lipedema problems started. This is essential to understand, because something that precedes the development of lipedema cannot be its cause. We have consistent data that shows the impact of psychological issues and of chronic stress on pain perception. This is highly relevant for patients with lipedema.

But in addition to these mental problems, there is also social pressure because of the current beauty ideal. I love the Spring *Pathways*, as 99.9% of magazine covers show very slim women with very slim legs. There are girls and women who believe if their legs don't look like these, they may have lipedema.



MYTH 3: Lipedema is primarily an edema problem and MLD is an essential treatment.

I would say this is the key myth because the name 'lip-edema' suggests that there is edema, for which the treatment—at least in Germany, Europe, and many countries—is MLD and decongestion. But if there is no edema, you don't need decongestion. Research from the 1940s that first mentioned lipedema states that only 20% of them had mild edema in the evening, or maybe in the hot summer months following prolonged standing. Many traditional experts say that lipedema is an edema disease and edema is the cause of the pain. But that makes no sense because then all patients with severe lymphedema would have pain too. And we know that is not the case.

No imaging techniques like CT, MRI, and high-resolution sonography have ever brought evidence for edema in patients with lipedema. Never. A multi-center study led by Tobias Hirsch³, who also is a member of the European lipedema expert group, using high-resolution ultrasonography, concluded that there is no fluid in lipedema patients. When we have no fluid we have no edema and when we have no edema we need no decongestion.

MYTH 4: Lipedema makes you fat.

There is a strong stigmatization and “fat-shaming” of obesity in society. For many severely obese people, it is a horrible situation. They get blamed for being obese. Yet obesity is a disease that has many complex causes. Particularly women experience stigmatization and discrimination because of their weight or body shape. This is an important reason why lipedema became much more popular in the last years. “I am not fat, I have lipedema”, is a credo for many patient and support groups that you will find on websites⁴. But there is no scientific evidence for this. Nor is there any pathophysiological concept for why lipedema should increase weight gain. Indeed, the opposite seems to be true. Weight gain and obesity is an essential trigger to get lipedema. At the Foeldi Clinic, more than 80% of patients with lipedema are obese. Other centres in Europe report similar numbers^{5,6,7,8}.



Before bariatric surgery (left), and after bariatric surgery (right). Lipedema in remission (patient free of complaints).



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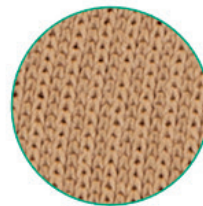
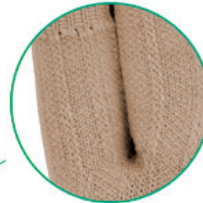
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MYTH 5: Weight loss has no effect on lipedema.

What is the pathophysiological concept behind this statement? When you lose weight why should you lose weight everywhere but not in the legs? We see many patients who lose weight (after bariatric surgery) in the legs because we take the measurements^{7,8} (refer to images on page 6).

MYTH 6: Liposuction leads to a marked and persistent improvement in lipedema.

With Dr. Nestor Torio-Padron, a professor and plastic surgeon from the University of Freiburg, we reviewed all the data and found that it is not only poor, but also all the data are provided by the doctors themselves who do the liposuction. Therefore we do not have any independent data.

I think a small group of patients may benefit from liposuction, e.g. those not severely obese, with a BMI of 30, with stable weight for many years and with no severe untreated psychological problems. If conservative

therapy isn't helpful (compression, exercise, weight management, and sometimes additional psycho-social therapy) these patients may benefit from liposuction. But liposuction makes no sense when they are severely obese, when they have eating disorders, when they are experiencing the yo-yo weight effect.

Q How do you think that your work and the consensus report will change the paradigm going forward?

I think that this European Lipedema Forum was a huge step that prompted many other initiatives. Dr. Hakan Brorson from Sweden incorporated the European Consensus and the article series on to the Swedish Lymphology Website. Together with the Dutch group, we are working on a fact sheet with Consensus results, which will be distributed in other European countries as well. A new website for professionals and patients will provide credible evidence-based information about lipedema. It is essential that patients receive information, which is

“scientifically-based” and not “interest-based”.

Prof. E. Foeldi, who wrote the original textbook on lipedema, has now changed her view and I'm very grateful for that. Many more important and credible opinion experts from 10 European countries support this new view.

I think a lot has happened in this short time frame. We are especially pleased that all the articles we published have been in the Top 10 rankings and are being read by a lot of people. I hope your readers will learn from these articles as well. **LP**

A full set of references can be found at www.lymphedemapathways.ca

Editor's Note:

A summary and update of the article series is published as a supplement in the *Journal of Wound Care* (October 2020). Prof. Hugo Partsch, the world-renowned phlebologist, wrote the foreword for this supplement.

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Anatomy and physiology of the lymphatic system

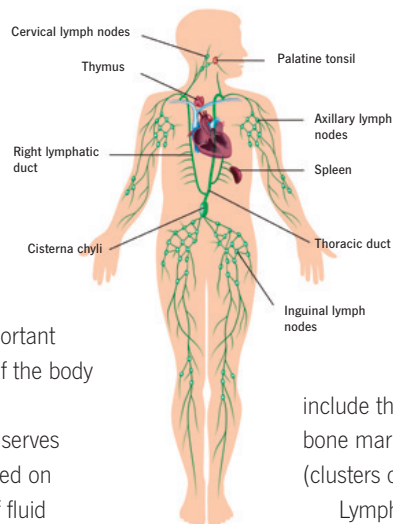
Knowledge, understanding and commitment are the keys to long-term success

By Kathleen Francis

Lymph nodes and lymphatic vessels were first observed around 2500 years ago by Hippocrates and others, and further work to describe and delineate the lymphatic system was done in the 1600s. However, the lymphatic system received scant attention in research and medical literature over the ensuing centuries, until the dawn of the 21st century. Fortunately, the last 25 years have seen an explosion of interest in the lymphatic system; anatomy, physiology, clinical pathology and important effects on other systems of the body and their disorders.

The lymphatic system serves essential functions, centered on immunity and transport of fluid and waste products. It is the primary route for transport of nearly all fluid that naturally filters from blood capillaries into spaces around and between the tissues (called the interstitial space) and is able to absorb and eliminate

proteins, fats, pathogens, metabolic debris and other waste products. The lymphatic system produces circulating white blood cells called lymphocytes that are essential in fighting disease by recognizing and attacking microbes, cancer cells and other antigens.



Components of the lymphatic system

The lymphatic system is present in nearly every part of the body and is composed of lymphoid organs, lymph nodes and lymphatic vessels. Lymphoid organs serve protective functions and

include the spleen, the thymus, tonsils, bone marrow, and Peyer's patches (clusters of immune cells in the gut).

Lymphatic vessels are comprised of successively larger components including initial lymphatics, lymphatic collecting vessels, and lymphatic ducts. Lymphatic vessels are found in all tissues of the body except bones, teeth, cornea and bone marrow. Lymphatic vessels are

often interlaced with or closely follow the veins and arteries of the blood circulatory system.

Initial lymphatics are divided into lymphatic capillaries and precollectors. Lymphatic capillaries are blind-ended finger-like projections composed of endothelial cells that loosely overlap and can lift open to expose gaps through which fluid and molecules enter. Increased fluid in the interstitial causes small filaments attached to the endothelial cells to "float away" and pull on the endothelial cells to open larger gaps and admit more fluid. Thus, initial lymphatics have an absorbing function, picking up fluid and various molecules from the interstitial and delivering them to the collecting lymphatics, which ultimately transport the lymphatic fluid to larger lymphatic ducts in the abdomen and chest and from there into the bloodstream through openings into the large veins near the neck. The fluid and waste material are subsequently eliminated from the blood through the kidneys, liver and bowel.

Lymphatic physiology

Because there is no heart to pump fluid through the lymphatic system as there is in the blood circulatory system, the lymphatic collecting vessels have smooth muscle and valves to ensure unidirectional flow even against gravity. Sections between valves are called lymphangions, and the smooth muscle in the vessel wall enables each lymphangion to



Kathleen Francis, MD has devoted most of her professional career to the evaluation and management of chronic edema and lymphedema. She is a member of the steering committee of the American Lymphedema Framework Project and serves as medical director of Klose Training and Consulting, LLC.

In a healthy lymphatic system, the more fluid that enters each lymphangion, the greater the amplitude and frequency of its contractions and the more fluid is moved forward.

spontaneously contract to force fluid into the next lymphangion, while the valves between them ensure forward flow and prevent lymphatic flow from going backwards.

This lymphatic “pumping action” is regulated by what are known as intrinsic and extrinsic factors. Intrinsic factors include smooth muscle contractility, hormones and other circulating substances, nerve factors, and distension of the lymphangions by fluid. Extrinsic factors include body movements and skeletal muscle contractions, respiration, blood vessel pulsations, and external pressure such as massage. Abdominal deep breathing may increase pumping in the larger central lymphatic ducts and create a “suction effect” that increases transport from the peripheral lymphatics.

Lymphatic vessels are distributed in two “layers”: both above and below the fascia, which drains the skin and subcutaneous tissues, and a deep system, which drains the muscles and joints. The superficial system has a larger capacity than the deep system and plays a greater role in disorders such as lymphedema. These two “layers” are connected by perforator lymphatics that link the two systems and may sometimes provide a “detour” when one system or the other is blocked or damaged. The superficial and deep systems merge into the larger lymphatic ducts before emptying into the large veins.

During this transport process the lymphatic fluid needs to be cleansed of harmful pathogens before entering the bloodstream. This filtering process occurs when lymphatic fluid flows through lymph nodes, clusters of which are mostly found at main articulations of the body such as the groin (inguinal nodes), armpit (axillary nodes), neck area (supraclavicular and cervical nodes), and intestines. There are between 400-700 lymph nodes in the human

body, with the number varying from person to person. Within the lymph nodes, bacteria, viruses, cancer cells, and other pathogens are filtered from the lymph fluid and destroyed by specialized immune cells in the nodes. When the lymph fluid leaves the node to enter the bloodstream it is, in normal circumstances, free of pathogens.

Lymphatic transport capacity

The amount of fluid that filters out of blood capillaries into the interstitium can vary greatly and place a greater transport load on the lymphatic system. An increase in the amount of blood in blood capillaries causes increased pressure inside the capillaries and forces more fluid out into the tissues. Some factors that increase pressure inside blood capillaries include heat, inflammation or local injury; chronic immobility and dependency of limbs; venous engorgement from damaged vein valves (known as chronic venous insufficiency); blood clots and heart failure. Increased fluid leakage from blood capillaries can also occur due to severely decreased protein levels in the blood as seen in kidney or liver disease, advanced cancer, and some nutritional disorders.

Nearly all of the 16-18 liters of fluid filtered daily from blood capillaries has to be returned to the systemic circulation by the lymphatic system. The lymphatic system has a maximal capacity for fluid transport that typically far exceeds these daily requirements, but this maximal capacity appears to differ between individuals. In most circumstances, the lymphatic system has plenty of spare capacity so that if extra fluid filters into the tissues, the lymphatic system can ramp up its function and take away the excess fluid before it accumulates and causes swelling.

However, swelling can occur transiently even in healthy individuals when the amount of fluid in the tissues temporarily exceeds even the maximal capacity of a healthy lymphatic system. For instance, an injury or surgery can cause local inflammation and tissue damage

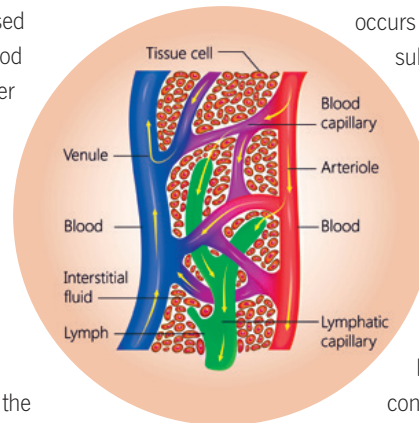
with increased local blood flow and leakage from damaged capillaries that overwhelms the local lymphatics temporarily. Over time the injury heals and the lymphatic system gradually eliminates the excess tissue fluid.

Chronic edema/lymphedema

Chronic swelling or lymphedema occurs mainly in three scenarios:

1 The lymphatic system in one or more areas of the body is damaged or dysfunctional so that its maximal capacity is insufficient to carry even a normal daily amount of fluid filtering into the interstitium. This may happen, for example, as a result of congenital (or inborn) defects in the lymphatic system as in primary lymphedema, or as a result of surgical removal or radiation of lymph nodes, obesity, certain types of severe extensive trauma, or in underdeveloped countries as a result of parasitic infection.

2 Too much fluid leaks out of capillaries into the tissues over a long period of time so that the chronically overtaxed lymphatics fail and suffer permanent damage. Typically, this occurs when blood capillaries are subject to chronic engorgement and increased pressure from “back-up” of venous blood in the capillaries, which forces excess fluid out over an extended period. This may occur in chronic venous insufficiency, venous blood clots (thrombosis), congestive heart failure, chronic



immobility and dependency of limbs, and certain types of liver disease, among others. Excess fluid may also filter out of capillaries when there is a chronically diminished blood protein level, as in some nutritional disorders or serious illnesses.

3 And, in the “worst-case scenario”, both of the above situations occur simultaneously. That is, an individual has an impaired or insufficient lymphatic system and there is increased fluid filtration from the blood capillaries.

Complications of lymphedema

In chronic edema or lymphedema, the long-term swelling with an accumulation of fluid in the interstitium (also known as fluid stasis)

triggers chronic inflammation and a series of molecular events in the affected area that can cause an overgrowth of fatty tissue, hardening and thickening of skin and subcutaneous tissue, rashes and redness, severe skin dryness, recurrent infections, and development of cysts, nodules, skin breakdown, and weeping. These complications tend to occur with greater frequency and severity in lymphedema affecting the lower extremities.

It is particularly important to understand the impact of obesity on the risk and severity of lymphedema. Studies have shown that obesity diminishes lymphatic function at baseline, increases inflammation in tissues, significantly increases the risk of developing lymphedema (including after cancer treatment), and predisposes to more severe skin and tissue changes once lymphedema is established.

Lymphedema treatment

Understanding the anatomy and physiology of the lymphatic system helps us appreciate

the factors and techniques that can treat and even prevent lymphedema.

We know that the longer fluid sits in the tissues without being removed the more inflammation, lymphatic damage, and tissue changes occur. We have seen that lymphatic transport is enhanced by massage, muscle activity, movement, formal exercise, and deep breathing. Activity may also help to prevent the onset of obesity, which we know can be a strong risk factor for lymphedema. We can see that moving or at least elevating the legs decreases the effects of gravity on the veins and lymphatics. Compression helps decrease the filtration of fluid from blood capillaries and reduce the load on the lymphatic system, and also stimulates lymphatic pumping. This knowledge also helps us understand why lymphedema experts strongly recommend detection and treatment of chronic edema/lymphedema as early as possible so that fluid stasis and its associated complications can be averted

or limited by treatment. Even relatively mild swelling, if it lasts more than several months, should be addressed.

Treatment of chronic swelling and/or lymphedema includes Complete Decongestive Therapy (CDT) with manual lymphatic drainage, compression bandaging, and long-term daily use of appropriate compression garments. Weight management, activity and exercise, skincare, elevation, and deep breathing also play an important role in lymphedema management. Hopefully this introduction to the anatomy and physiology of the lymphatic system will help those who suffer from chronic edema/lymphedema and their carers to appreciate the reasons for, and the importance of, treatment and long-term self-care. Knowledge, understanding, and commitment are the keys to long-term success. **LP**

A full set of references can be found at www.lymphedemapathways.ca



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By Marize Ibrahim and Angela Yung, Illustrations by Stephen Chan

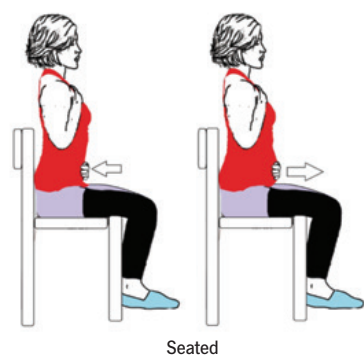
Muscle contractions enhance lymphatic drainage, which is why daily exercise is strongly encouraged for patients with lymphedema. When starting any exercise, start slowly, and progress gently, as your body adapts to the regimen. Incorporate exercise as part of your daily routine to optimize your health and maximize benefits on your lymphatic system. Compression bandages or compression garments should be worn during the exercises.

Ensure you maintain a good posture throughout each exercise. Walking is a great exercise. Start with two minutes each day as your legs can be heavy with the edema. As your muscle endurance improves, along with your lymphatic pump mechanism improvement, you will notice a reduction in the feeling of heaviness in the legs.

The following is a modified exercise program, adapted from Casley-Smith principles¹, that can be done easily during

the day; however please speak with your lymphedema therapist to have the program customized appropriately for you. Remember, the exercises should not be painful. Aim to do 3-5 repetitions of each exercise, which should take approximately 20 minutes.

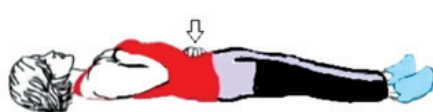
All exercises can be done either sitting or lying down, however, if possible, lying down is best, as gravity works against you in lower extremity lymphedema.



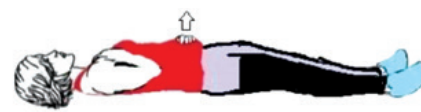
Seated

1 Abdominal breathing exercises

- Relax your neck and shoulders while placing one hand on your upper chest and the other on your stomach.
- Take a deep breath through your nose and feel the hand on your stomach move out (the other hand on your chest should not be moving).
- Breathe out slowly and as long as you can until you exhale completely (the hand on your stomach should move inward with the exhale).

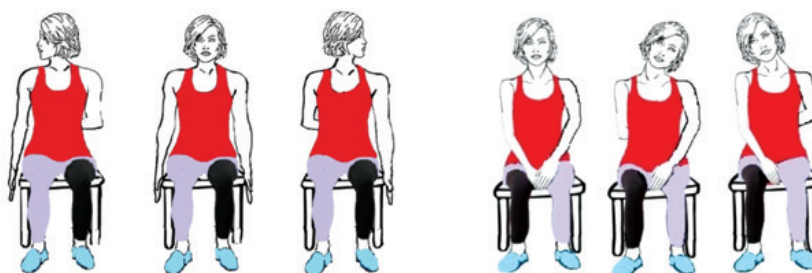


Lying Down



2 Neck range of motion exercises with deep breathing

- Turn your head slowly to the right as far as you can while you inhale then return to center as you exhale, repeat on the left.
- Move your right ear towards your right shoulder as far as you can while you inhale and then return to center, repeat on the left.

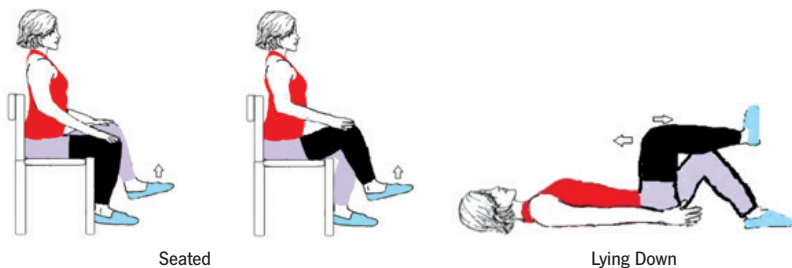


Seated



Lying Down

Angela Yung, BSc, PT, ALT and **Marize Ibrahim MSc, PT, CDT (CS), ALT**, Clinic Specialist-Oncology. Both Lymphedema therapists work at the McGill University Health Center (MUHC) Lymphedema Program in Montreal, Quebec. A special thanks to **Steven Chan B.Ed., MEd.** Freelance Illustrator

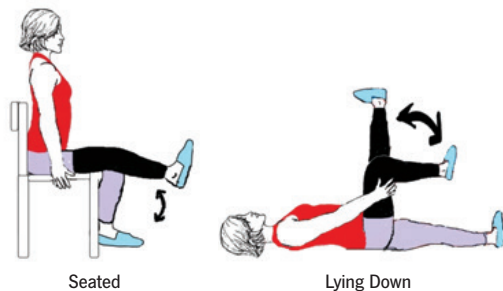


3 Hip tucks with deep breathing

- Keep left leg bent, do the abdominal breathing (Exercise # 1) and while you exhale, lift the right leg up towards your chest, and then slowly back down.
- Alternate and do the opposite, this time bending the right leg and lifting the left leg up with abdominal breathing, and then slowly back down.

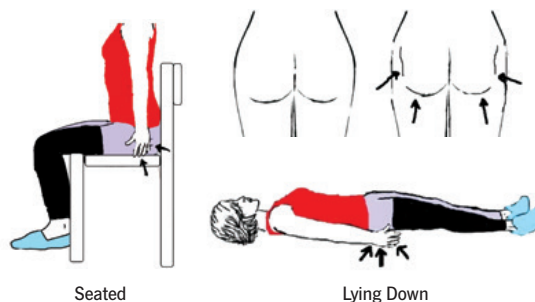
4 Knee kicks

- Do the abdominal breathing (Exercise # 1) and while you exhale, lift right knee straight out and relax.
- Alternate by straightening left knee out, using the same rhythmic sequence with abdominal breathing.



5 Buttock squeezes

- Do the abdominal breathing (Exercise # 1) and while you exhale, contract (squeeze) the buttock muscles for the “duration” of the breathing, and slowly relax the contraction.



6 Ankle pumping (can be done sitting or with legs up against a wall.)

- Do the abdominal breathing (Exercise # 1) and while you exhale, point your toes for 3 seconds then bring your toes towards you for 3 seconds.
- If it's easier, you can do one foot at a time, as you don't need to do both feet together, however ensure you use the same rhythmic sequence with abdominal breathing.



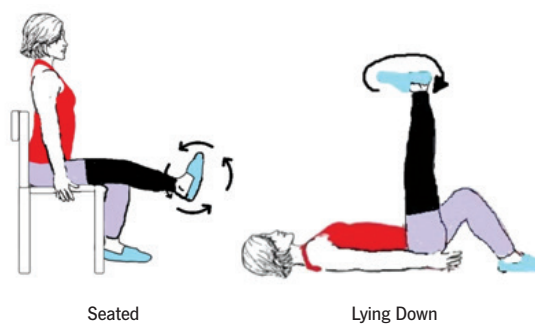
7 Air circles

- Keep left leg with a knee bent (or bent at 90 degrees if in a chair), do the abdominal breathing (Exercise # 1) and while you exhale, make circles with right leg in one direction then the other direction.
- Alternate legs using the same rhythmic sequence with abdominal breathing.



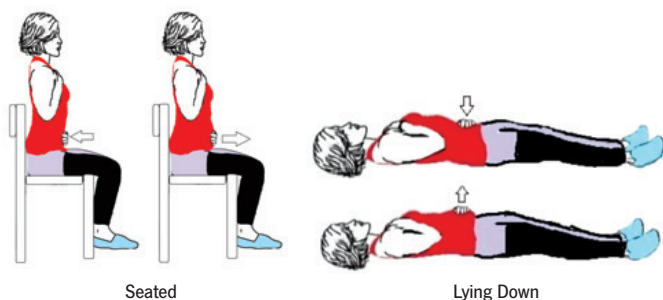
8 Air cycling

- Imagine you are riding a bike in the air, do the abdominal breathing (Exercise # 1) while you circle your legs one at a time to mimic the motion of riding a bike.
- Alternate legs, while using the same rhythmic sequence with abdominal breathing.



9 Abdominal Breathing

End your session as outlined in Exercise 1.



Editor's Note:

These exercise examples can be integrated into educational information given to patients as part of a self-management program.



LYMQOL: Measuring the effect of lymphedema on quality-of-life

A comprehensive questionnaire

By Vaughan Keeley and Katie Riches

People with lymphedema are fully aware of the impact it has on their lives. In the past, lymphedema has been considered a rare condition, which is untreatable but not fatal and does not cause any significant impact on a person's life. As a result, in many countries, health service provision for the diagnosis and treatment of lymphedema is often limited.

When we first started our lymphedema service in Derby, UK, we quickly became aware of the significant impact that lymphedema had on people's lives but that it was also difficult to measure this in clinical practice. Some work had been published using established general health-related quality-of-life assessment tools but there was no established tool in English, which was specific to lymphedema. Therefore, we decided to develop and validate such a tool for adults with lymphedema. This became LYMQOL.

What do we mean by quality-of-life?

What someone feels is important to their quality of life (QoL) varies significantly from person to person and in any individual, may vary at

different stages of their life. For example, family, health, lifestyle, home, work, leisure activities, and financial security may feature in the list. As such, QoL is very difficult to measure in an accurate quantifiable way, which can be applied to everyone. Nevertheless, various approaches to this have been taken over the years and the important ones to consider here, are those which attempt to measure health-related quality-of-life.

Health-related quality-of-life (HRQoL) assessment tool types

1) General. These measure the general impact of ill-health and can cover all diseases, e.g. heart disease, neurological conditions, cancer. An example of a general HRQoL tool is the Short Form (SF-36) Health Survey, which has been used in some studies of lymphedema. The main advantage of these is that they allow comparison of the impact on QoL caused by different diseases. The main disadvantage is

that they are not able to look at the detailed impact of individual diseases, which can affect specific areas of QoL.

2) Condition-specific. These are designed to measure the impact of specific diseases and conditions on QoL e.g. lymphedema, heart disease, neurological conditions but there are separate questionnaires for each condition.



LYMQOL is an example of a condition-specific QoL tool

The main advantage of these tools is that they can give a more detailed description of the impact of

specific conditions on QoL. The main disadvantage is that they cannot easily be used to compare one condition with another.

In some research studies, both types of tools are used to give a detailed picture of the impact of a condition such as lymphedema on QoL. Further examples of the use of QoL tools in lymphedema can be found in Keeley (2016)¹.



Vaughan Keeley is a Consultant Physician in Lymphedema in Derby UK and Honorary Professor at the University of Nottingham Medical School. His research interests include QoL tools for lymphedema, breast cancer lymphedema, lymphedema in multiple sclerosis and lymphedema in obesity.



Katie Riches is a research nurse specialising in lymphedema. She recently completed her PhD looking at the assessment of breast lymphedema after breast cancer treatment. Her research interests include breast cancer lymphedema, measurement of lymphedema and primary lymphedema.

The structure of QoL tools

QoL tools are commonly questionnaires divided into sections known as domains. Each domain covers a particular aspect of HRQoL such as physical functioning, symptoms, emotional issues, social functioning and mental health. Within each domain there are a number of questions which cover different aspects of that domain, e.g. in the symptom domain one question may relate to pain. Each question is

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¹ Moffatt C et al (2012) 'A preliminary randomized controlled study to determine the application frequency of a new lymphoedema bandaging system' British Journal of Dermatology 166.3: 624-632. 3M, Coban and 3M Science, Applied to Life, are trademarks of 3M. Used under license in Canada. Please recycle. © 2019, 3M. All rights reserved. 1911-16116-E

scored by patients to indicate how much they are affected by the topic addressed by the question, e.g. the severity of pain.

On completion of the questionnaire, scores for each domain are added to give an overall score. The advantage of having domains is that it allows different aspects of QoL to be assessed separately. In some questionnaires there is a general question, which asks patients to give an overall QoL score as well.

How did we develop LYMQOL?

It is important that a QoL tool is designed in a rigorous way, which ensures that it gives as accurate a picture of QoL as possible. This involves a process of validation. It is a complex process, which involves a number of statistical techniques, the details of which are beyond the scope of this article. However, those interested in exploring this further can check the references at the end of this article.

In summary, the process of validation aims to examine three main areas:

- **Validity:** Is the tool measuring what it was designed to measure?
- **Reliability:** Does the tool produce similar results under different conditions? Are the results repeatable?
- **Responsiveness:** Does the tool detect significant changes, e.g. improvement after treatment?

From our experience in seeing patients in our clinics, we recognized that some of the issues facing people with lymphedema of an arm may be different from those with lymphedema of the leg, e.g. for those with arm lymphedema there may be an impact on everyday tasks where using the arm is involved e.g. getting dressed, combing hair, whereas for those with lymphedema of the legs, problems with walking and getting shoes to fit may be significant. We therefore decided to create two separate LYMQOL tools: one for arm swelling and one for leg swelling. However, some aspects affect people with lymphedema regardless of the anatomical site - such as an effect on their mood or symptoms such as pain. Therefore, some domains/questions are common to both tools.

The section on mood was taken from an existing validated HRQoL tool (the EORTC QLQ C-30, a tool designed for people with cancer)

with permission of the authors.

The first part of the validation involved sending drafts to a number of patients to seek their views as to whether we had covered all the areas which were important to them and also whether the questions were clear. The questions were then modified as necessary.

It is very easy to generate a large number of questions to try to cover all eventualities but this results in a very long questionnaire, which is difficult for people to complete. One of the aspects of the validation process was to reduce the number of questions by excluding those which tended to be scored the same. For example, a limitation of the ability to raise an arm up may result in difficulty putting on clothes but also difficulty with other tasks such as combing the hair. Therefore, to obtain a measure of the ability to raise the arm only one of these questions needs to be asked.

Example question from LYMQOL-Arm

How much does your swollen arm affect the following daily activities - occupation?

Not at all / a little / quite a bit / a lot

The scoring system was something we had to consider as well. Many questionnaires have a numerical scoring system whereas others have a number of categories, often 4. We opted to use the category system for ease of scoring and an example of one of the questions from LYMQOL-arm.

There are four domains in both LYMQOL-arm and LYMQOL-leg covering symptoms, appearance, function, and mood. We also included a numerical overall QoL score rating from 0 (poor) to 10 (excellent).

There are 33 questions in LYMQOL-arm and 34 in LYMQOL-leg. Patients find these relatively quick to complete—in a matter of minutes.

In what circumstances can LYMQOL be used?

We designed LYMQOL with the aim that it could be used for both clinical purposes and in research. It can measure the impact of lymphedema before treatment but also can

Example questions from LYMQOL-Leg

How much do you feel the swelling affects your appearance?

How much difficulty do you have finding clothes to fit?

Do you have difficulty finding shoes to fit?

Does the swelling affect how you feel about yourself?

Does it affect your relationships with other people?

be used to measure changes in QoL, for example following treatment.

1 In the clinic. It can be used with individual patients to assess the impact of the condition on their quality-of-life and also to monitor changes following treatment. It can be used in clinical audit as a patient rated outcome measure (PROM), which can help a service to determine its impact on its patients' QoL. In our clinic we use a combination of LYMQOL, limb volume measurements and the frequency of cellulitis recorded before and after treatment, to measure the outcome of our treatments.

2 In research. It can be used to measure the impact of chronic oedema/lymphedema on patients; QoL in a variety of settings, e.g. in the International Lymphedema Framework's LIMPRINT study. It can also be used to measure the outcome of new treatments/interventions and their impact on QoL, e.g. it has been used in studies of lymph node transfer, lymphovenous anastomoses, yoga and exercise.

The interpretation of LYMQOL scores

Many patients with lymphedema also have comorbidities, which can affect their QoL, e.g. heart disease, neurological conditions, diabetes and respiratory disease. It can, therefore, be difficult to separate the effect of the lymphedema on QoL from the effect of these other conditions. For example, if a patient with a neurological condition and limb weakness develops edema in the affected limb, the limb weakness may not improve significantly even if the edema is completely

resolved with treatment. Therefore, some interpretation of the LYMQOL results is required in these. The use of other measures, e.g. limb volume reduction and a reduction in the incidence of cellulitis, can also help to determine a positive outcome of treatment in this example.

Current use of LYMQOL

We have been pleased with the widespread interest in LYMQOL internationally. It is currently used by 200 registered teams from 24 different countries, and is most commonly used in the UK, USA, Australia and Canada. Translation has been completed in Swedish, Norwegian, Portuguese, French, Swedish, Turkish, Danish, Dutch, Japanese and Italian to date and others are in progress.

To use LYMQOL, a member of the requesting team submits a completed registration form. Users are asked to identify how the tool(s) will be used - i.e. in clinical practice, audit or research studies. LYMQOL

is most commonly requested as a clinical tool by lymphedema teams, before and after lymphedema treatment, to help assess the impact of the treatment(s) given. Enquiries from those interested in using LYMQOL / registration can be addressed to katie.riches@nhs.net. There is no charge for its use.

New developments in LYMQOL

The initial LYMQOL tools were designed to assess QoL in people with arm and/or leg lymphedema. We realized that using only these two versions meant that we weren't able to assess QoL in all of the patients that we see in clinic, particularly those with lymphedema affecting the mid-line (head and neck, breast, genitalia). Our service also sees patients with lipedema and although LYMQOL- leg may address many of the issues faced by women with lipedema, the tool has not been tested formally in this patient group. We are therefore working on the development and validation of new versions of LYMQOL.

The Breast LYMQOL is the most developed and has recently been validated. The development and validation process mirrored that for the arm and leg tool. Patients who had all undergone breast cancer treatment with some having breast lymphedema and some who did not took part in the validation study. The new tool was compared to a recognized QoL tool. Analysis showed that similar to the arm and leg versions, Breast LYMQOL is a valid and reliable tool. This will be published and available shortly. We are also working on validating head and neck lymphedema and Lipoedema (LIPQOL) tools. [LP](#)

A full set of references can be found at www.lymphedemapathways.ca

Editor's Note:

The LYMQOL tool is easily assessable through the CLF HP Toolkit that can be assessed through www.canadalymph.ca



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Working my way through the lymphedema journey

An introspective look back

By Anna Kennedy



The year was 1999. I was a 43-year-old wife and mother, raising two young daughters, while juggling the responsibilities of a busy career with American Express. My role as Director of Training and Communications required frequent travel within North America. Suddenly in April, my life changed drastically with three strikes within a three-week period.

- Strike 1** – My 73-year old father was diagnosed with inoperable lung cancer
- Strike 2** – My entire office department was being restructured into the USA and we all lost our jobs
- Strike 3** – A diagnosis of advanced cervical cancer stopped me dead in my tracks

I believe in silver linings—and so the benefit of losing my job just before getting sick was that I didn't have to worry about work-related responsibilities and could focus on my health while spending time with my husband, children, and my terminally ill father. He died in October of that same year, but not before we spent a lot of quality time together,



Anna Kennedy is the Editor of *Pathways* – Canada's lymphedema magazine. She was a founding member and led the Canadian Lymphedema Framework as Executive Director from 2009-2019. In 2012, Anna was awarded the Queen Elizabeth II Diamond Jubilee Medal in recognition of her leadership and contribution to the lives of Canadians.

including driving each other to cancer-related appointments. I will always be grateful for our special bond that was strengthened during that difficult time.

During that same summer, a radical hysterectomy plus pelvic lymph node dissection was the treatment protocol to deal with my cancerous tumour. A total of 23 lymph nodes were removed from my pelvic region. Surgical complications delayed my recovery. Reconstructive surgery to repair a severed stent and bladder further damaged scar tissue and put me at an even greater risk of lymphedema (unbeknownst to me at the time). It took almost a year before I was fully recovered and back at work full-time. I was fortunate to find another job within American Express as Head of Network Relations. It meant more travel, negotiating and liaising with American Express franchise travel agency owners around the world, but it was something I really enjoyed.

In the meantime, I diligently continued follow-up checkups with my surgical oncologist every six months. Several times after returning from a long international flight, I remember mentioning that my left foot was slightly swollen. My surgeon dismissed my concerns with comments such as “many people

experience ankle swelling after sitting on a plane. It's not something to worry about.”

Fast forward five years and I was working in a new role with a new company (Indigo-Chapters) as Vice President of Retail Training and Customer Service. I had celebrated my 5-year cancer survival and put my cancer journey behind me. I was again focused on my career and living a healthy life, grateful for the second chance I was given. Then literally out of the blue—I woke up one morning and saw that my left foot and leg were extremely swollen. I couldn't fit a shoe on or wear dress pants. I immediately assumed my cancer was back and somehow responsible for the swollen leg. My family doctor was as concerned and perplexed as I was. It took many frustrating months of diagnostic tests to rule out



any cancer recurrence. One night in desperation I typed, “swollen leg post-cancer” into my search engine and up came the word “lymphedema”. I had never heard the word before and didn't even know how to spell or pronounce it. I conducted a diligent Internet search to learn more and shared the research findings with my

family physician. She warned me to be wary of dubious Internet sources. However, I shared the two best sources I had discovered; those of the Mayo Clinic and Stanford University. According to the literature, I had 9 out of the 10 risk factors! After a frustrating process of getting a diagnosis and treatment referral, I was finally on my way to managing the problem. I got involved in the lymphedema community and found my passion in sharing knowledge with others to make their lymphedema journey easier.

Fast forward once again—but this time to 2020. After twenty years cancer free, I am still living with lymphedema, but am grateful that it led me to the second chapter of my career.



I left the corporate world in 2006 and jumped into the non-profit and charitable sector. At one point I was simultaneously involved on a provincial, national and international level within the lymphedema community.

I've met many people along the way in my lymphedema journey and have learned from all of them. I've learned that people who complain about their lymphedema and focus on negative situations drain my energy and are the people I try to avoid. I've learned that the wonderful health professionals who I've worked with across the globe are true heroes. All of them who run National Frameworks or the International Lymphoedema Framework have full-time jobs as clinicians and then spend their evenings and weekends trying to improve the lives of lymphedema patients by advancing lymphedema care. I've learned that after 10 years of running the Canadian Lymphedema Framework, a new change is required with fresh ideas and new direction. I wish the Board of Directors all the best and will always support them from the sidelines and cheer them on.

In the meantime, I'm excited about the next chapter in my life. After retiring as CLF Executive Director in December 2019, I have

more time for competitive tennis, to connect with friends and family, to plan my daughter's wedding, enjoy gourmet cooking and to go back to university to study Interior Decorating. I still manage to fit specific lymphedema related projects into my lifestyle. One of the current projects is continuing on as *Pathways Magazine* Editor. It's the role I have always enjoyed the most and brings me back to my earliest days in the publishing industry before I started at American Express. I enjoy connecting with the lymphedema opinion experts around the world. I love working with our publisher and the creative element of bringing author submissions come alive in the magazine. I like the relationships with advertisers and I am excited about all the possibilities ahead in expanding the magazine to a North American and international audience. There is plenty more to do and my volunteer time will be filled to the brim.

I continue to ensure my health comes first and lymphedema management is something I prioritize. There are many things that help me in that journey. Here are just some of my lessons learned:

- ✓ **Whatever life throws at you.** It is a positive attitude and the acceptance and the support of family and friends that will get you through much easier.
- ✓ **Compression became my friend.** I am 100% compliant in wearing my full leg stocking religiously. I've learned the consequences of not wearing compression and how it takes me right back to where I started in reducing the swelling and stabilizing the leg. I don my stocking after brushing my teeth in the morning and remove my stocking after brushing my teeth before bed. Full stop—end of story.
- ✓ **Be proud.** I don't hide my compression anymore. It took me 15 years of living with lymphedema, to realize that most people don't notice my compression stocking and if they do—it starts a conversation. I've finally expanded my wardrobe again; going back to pretty dresses, and no longer resigning myself to wearing long pants and skirts.
- ✓ **Learn all you can about cellulitis.** It's a serious threat for all of us living with lymphedema. I've contracted it twice and learned the hard way to identify it as soon as possible and advocate for the proper antibiotics. I also travel with a supply of

antibiotics in the event I develop this infection away from home.

- ✓ **Exercise is crucial.** Stay fit; move regularly, regular walking, weights and yoga. Find something you love. For me, taking up tennis has not only helped move my lymphatic fluid—but also enabled me to make new friends and learn to have fun while staying fit.
- ✓ **Stay informed and question everything.** If someone says its good for you—do your own research. Weigh the pros and cons and read the scientific research to support any claims.
- ✓ **Get involved.** Whether it's donating your money or your time. Your provincial or national lymphedema organizations need people like you to help them in their cause. I promise you that you will gain much more than you can ever give. **LP**



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Hints and Tips

Wear disposable gloves

If you have access to disposable gloves, wear those over your compression glove while out of the house to prevent your compression garment from becoming contaminated. Carefully remove and dispose of the gloves once you're at your destination.

Source Lymphie Life.com



Source: Lymphie Life.com

Wash exposed garments daily

It's best to check your garment's washing instructions, although most can be machine-washed and dried on the gentle cycle, or air-dried.




Moisturize

Frequent hand-washing can lead to dry skin. Continue to moisturize with a PH Balanced lotion to avoid dry, cracked skin and minimize the risk of cellulitis.



Beat the heat

Walking in the morning or evening to avoid the highest temperatures of the day means you will reduce uncomfortable sweating while wearing your garment and may reduce the amount that you need to wash it. 



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Did You Know?



Assessment of LE clinical practice guidelines

To determine the methodological quality of current lymphedema clinical practice guidelines (CPGs) to assist healthcare professionals in selecting accessible, high-quality guidance. Reviewers used the Appraisal of Guidelines for Research and Evaluation II (AGREE II) instrument. **Results:** Of the 6 relevant CPGs identified, no CPG achieved an overall scaled quality score of $\geq 80\%$, with the top CPG scoring 79.2%. **Conclusions:** According to the defined threshold, no LE CPG was considered adequate for use in clinical practice and all have areas for improvement. A structured approach, guided by the use of CPG creation tools, should help CPG development groups in improving the quality of future CPGs.

J Vasc Surg Venous Lymphat Disord. 2020 May 23; PMID: 32454237

Comparing the experience: primary and secondary lymphedema

To describe and compare the experience of individuals with primary and secondary lymphedema, 19 patients (8 primary and 11 secondary lymphedema), participated in a study, using unstructured and semi-structured interviews. **Results:** The findings suggest differences between the experience of living with primary or secondary lymphedema. Also, those with lower extremity lymphedema have more pain, fatigue, and functional limitations. **Conclusions:** The experience of living with lymphedema involves aspects of fear, suffering, coping, and management of the disease and differs between secondary and primary causes. However, it seems to be more dependent on its location than its cause.

Braz J Phys Ther. 2020 Jun 01; PMID: 32518025

Cording after BC surgery: higher risk of BCRL

To identify the association between cording and breast cancer-related lymphedema, 1181 patients were prospectively screened for BCRL after breast cancer (BC) surgery, using patient-reported outcome measures and perometric arm volume measurements. **Results:** 31.7% of patients reported cording first, a median of 4.5 months postoperatively. Patients who reported cording had 2.4 times the odds of developing BCRL compared to those who did not, and most frequently reported tenderness (61.2%), aching (60.7%), and firmness/tightness (59.8%). **Conclusions:** Patients reporting cording are at higher risk of BCRL. Cording should be incorporated into BCRL risk stratification. [LP](#)

J Surg Oncol. 2020 Jun 04; PMID: 32497273



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10th International Lymphoedema Framework

Conference: The 2021 Symposium will highlight innovative ideas and research in lymphoedema management. ■ www.lympho.org

May 14-16, 2021

Gold Coast, Australia

2021 Australasian Lymphology Association

Symposium: Join us for the 2021 ALA Symposium, where together we will be exploring new pathways.

■ www.lymphoedema.org.au

During the COVID-19 pandemic, in-person conferences have been cancelled or delayed until 2021. However many organizations are offering online symposiums, webinars and other virtual learning opportunities. We suggest you check the websites of the Canadian Lymphedema Framework (www.canadalymph.ca), plus your provincial lymphedema association and the following international organizations, known for offering educational opportunities:

Australasian Lymphology Association
www.lymphoedema.org.au

International Lymphoedema Framework
www.lympho.org

Lymphatic Research and Education Network
www.lymphaticnetwork.org

Lymphoedema Support Network
www.lymphoedema.org

National Lymphedema Network
www.lymphnet.org

British Lymphology Society
www.thebls.com



Your COVID-19 stories

Her lymphedema diagnosis caused by previous breast cancer surgeries didn't stop her from a path to help others. Leda Raptis, a professor in the Department of Biomedical and Molecular Sciences at Queen's University in Kingston, Ontario was concerned about the lack of protective equipment in the ICUs during this COVID pandemic. So, she sat down at her sewing machine and got to work making masks for the healthcare professionals who needed them to help others.

In 2010, Raptis was diagnosed with breast cancer and went through the treatments including surgery, nodal dissection, chemotherapy, and hormonal therapy. Soon after she developed lymphedema, and her compression therapy was initiated. She had to make several modifications herself to her compression garment sleeves and gloves (e.g. bringing the thumb in a natural position, adding a small cushion in the inside of the glove) to adjust them perfectly to her arm anatomy. Several infections (cellulitis) to her arm made the lymphedema challenging to control, however, a visit with Dr. Anna Towers really helped reduce the incidence of infections and manage her lymphedema.

So, with her lymphedema under control and a skill set that's much needed during this pandemic, she started sewing. With the help of her husband, Kevin Firth cutting the material, it takes Raptis about three minutes to sew each mask, to the tune of up to 50 per day. She made over 300 masks for hospital staff, until proper shipments arrived and hers were not needed anymore. She accomplished all that with a well-fitting, compression glove and sleeve on! Later, as the laboratories at the university were starting to re-open, her colleagues requested masks for their students. They wanted to pay her for them, but instead, she told them to make a donation to Breast Cancer Action Kingston, and later to the Ontario Health Coalition. Then in June, the horrific murder of George Floyd happened and the donations went to Black Lives Matter, in the name of those affected by this issue, including her dear students and colleagues. Raptis has made over 780 masks total so far, with 160 ready to go, plus several more for children.

Raptis is not alone in her enterprise. Once community members heard about her kind efforts, elastics were donated to her, at the time when there was no elastic anywhere in sight! She feels so blessed for the help of Dr. Towers and her team who made it possible to manage her lymphedema and in turn be able to give back to her community by helping others during this COVID pandemic.

(Written by Marize Ibrahim (Montreal Quebec), following an interview with Leda Raptis.)

As a team of Healthcare Professionals, we have been working hard to put our patients' safety, wellness, and trust as our top priority. When the Manitoba government gave us the green light to open, our staff did not miss a beat. We called a next day meeting. Together we worked hard at getting the last-minute details and supplies set up. We increased our sanitizing protocol, and were happy to realize that we had already been doing most of what is now required as part of our regular high standards of patient care. Wearing masks for our patients' safety is certainly a new protocol but one that we willingly adhere to.

*Linda Menzies,
Morden Massage Therapy in Manitoba*

Canada's Lymphedema Magazine

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The Canadian Lymphedema Framework (CLF) wishes to thank our Industry Partners and Pathways Sponsors for their financial support in making this magazine a reality.



About the CLF: The Canadian Lymphedema Framework is an academic and patient collaboration, working to improve lymphedema management for lymphedema and related disorders in Canada.

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