

Canada's Lymphedema Magazine

Pathways

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FALL 2018

**Laser
therapy**
Lymphedema
related
symptoms



**Addressing
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Busy times as the colourful days of fall approach

As the warm weather draws to a close, we are wrapping up a busy summer season at the Canadian Lymphedema Framework. In addition to our quarterly magazine, we are working on some exciting new projects that will build our education tools library. We hope to share some of these tools in our next issue.

The fall issue of *Pathways* features a varied selection of articles from researcher, clinician, therapist and patient perspectives. As always, we hope to strike the balance of including interesting topics for both patients and those professionals who support their care.

Professor Sheila Ridner from Vanderbilt University shares her research on the most commonly reported symptoms related to lymphedema, going beyond swelling and fluid accumulation. Her team has developed symptom assessment tools that help determine what patients are experiencing. Recognition of these self-reported symptoms provides a voice for patients and can guide clinicians, who treat the disease, to address the pertinent symptoms as well.

Living with lymphedema causes its own challenges when it comes to clothing, shoes and other attire. Naomi Dolgoy is an occupational therapist who deals with lymphedema patients every day. She provides innovative and practical suggestions for adaptations to make life easier and enable increased independence for people living with lymphedema.

Complete Decongestive Therapy (CDT) is still considered the “Gold” standard of lymphedema treatment. In our Ask the Expert section, physiotherapist and educator Guenter Klose outlines what each part of this treatment protocol entails and stresses the importance of full CDT for best possible outcomes.

In addition to the “Gold” standard of care; several newer and innovative therapies are being used. One is Low Level Laser Therapy. While it is great to explore new treatment protocols, there is always a balance between those that are evidence based and those that have only clinical support. Three authors from Alberta have conducted a literature review of Laser Therapy to help you critically assess whether the treatment is right for you or for your patients.

Clinical guidelines are an essential tool for health professionals treating lymphedema to properly assess their patients. However when the Canadian Lymphedema Framework (CLF) surveyed therapists and nurses working with lymphedema patients (2009), an alarming 60 percent reported that they do not refer to clinical guidelines in their practise. Pamela Hodgson, a member of the CLF Education Working Group, highlights the usefulness of these tools in everyday practise in her informative article. The algorithm for adapting compression for different patient groups has been reprinted for your convenience, as a handy pullout for clinical



Pathways Editor Anna Kennedy and Summer Intern Emma Parry meet with Helmut Dostal of BCS Publishing to plan future magazines and projects.

practise. The decision making models in these guidelines help both novice and experienced therapists and clinicians to choose the best treatment path for their patients.

Exercise is not only good for the body, but helps many patients living with lymphedema feel better about themselves. Giselle DeVarenes shares her story on how the opportunity to work with both a life coach and a fitness coach helped her transition from someone who hid and lived in a cocoon to being the best version of herself (the butterfly). We hope her message will inspire others to take similar challenges.

Lastly, our readers told us in a survey last fall that keeping up to date on research developments in the world of lymphedema was most important to them. Keeping this in mind, we continue to expand the Did You Know section of *Pathways*, when we can. The highlights are only snippets and a summary—so we encourage you to read more by checking out the references and sources provided. [LP](#)

Anna Kennedy

Coming Soon:

The launch of a new CLF Health Professionals - Website Portal

Here's a hint of what's to come in the toolkit:

- Lymphedema related case studies from fellow health professionals
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- Assessment tools to help your practice

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Pathways
 Empowering patients and professionals

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Low level laser therapy: Lighting up the facts

A review of laser therapy for lymphedema

By Sapphire Kroetsch, Courtney Whitehead and Margaret McNeely

Introduction

Laser therapy is used by some physiotherapists in the treatment of lymphedema. This article provides an overview of the treatment protocol and by reviewing the published research literature, helps us understand the evidence supporting the effectiveness of this therapy.

What is a Laser?

A laser is a light that is concentrated in a tube until it becomes a narrow and powerful light beam. Lasers are commonly used in our daily lives including in homes (e.g. CD and DVD players), offices (e.g. laser printers), and at the store (e.g. bar code scanners). Moreover, lasers are used for cosmetic (e.g. remove birthmarks or

tattoos), therapeutic (e.g. wounds) and surgical procedures (e.g. laser eye surgery). The name “Laser” is an acronym for Light Amplification by Stimulated Emission of Radiation.¹

What is Low Level Laser Therapy (LLLT)?

Low level laser therapy (LLLT) is a treatment in which low powered laser light is applied to the skin of injured tissue or a body part to stimulate healing.² In the case of LLLT, the light particles are absorbed into the tissue without producing heat.² This is why LLLT is often referred to as “cold laser”. Low levels of near-infrared or red-beam light may be used.³ LLLT is a treatment to help healing of wounds and soft tissues, reduce

inflammation and address acute and chronic pain. Practitioners providing LLLT to patients are required to take specialized training and certification. Typically in Canada, licensed physiotherapists and chiropractors administer LLLT to patients. Table 1 (see page 6) provides a list of the different classes of lasers and the associated risks to the eyes and skin.¹

How does LLLT work?

The tissue absorbs specific wavelengths of light released by the laser. LLLT is believed to break down fibrotic tissue and to prevent scar adhesion to underlying healthy tissue.⁴

In the case of lymphedema, a therapist may consider the use of laser therapy as an add-on to the treatment care plan when the patient has a significant amount of thick, hard scar tissue under the skin, known as fibrosis.⁵ LLLT is believed to help lymphedema by breaking down the fibrosis.⁶ If the fibrosis is reduced, the tissue of the limb will feel softer and move more easily.⁶ In theory, if the tissue is more mobile, lymphatic flow is enhanced.^{2,3}

What does treatment with low level laser therapy involve?

The therapist will place a small, hand-held laser device directly on the skin surface. Protective eyewear is worn by both the patient and therapist to prevent accidental exposure to the eyes, that can lead to eye damage. Generally, several

Low level laser therapy is a treatment in which low powered laser light is applied to the skin of injured tissue or a body part to stimulate healing.



Sapphire Kroetsch, BKIN, worked as an Exercise Specialist in the Cancer Rehab Clinic under Dr. McNeely. Sapphire is in her first year of her Master's of Science in Physical Therapy at the University of Alberta.



Courtney Whitehead, BSc Kin, is a practicum student and research assistant in the Cancer Rehabilitation Clinic, Faculty of Rehabilitation Medicine at the University of Alberta.



Margie McNeely, PT MSC, PT, PhD is an Assistant Professor in the Department of Physical Therapy at the University of Alberta and Cross Canada Institute with research interests in the area of cancer rehabilitation and exercise. She is a Board member of the Canadian Lymphedema Framework.



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areas of the skin will be treated for between 20 seconds and one minute each, totalling a treatment time ranging between 10 to 30 minutes.⁶ Treatment frequency can range from 2-5 sessions per week for the first couple of weeks and will decrease over time depending on the individual's response to treatment.⁶ Typically, a minimum of a 4-week treatment period is recommended.⁷

What does LLLT treatment feel like?

Some individuals report feeling slight warmth or a tingling sensation when LLLT is applied; however, most do not feel anything during the treatment.⁶

Is LLLT safe?

LLLT is non-invasive, and if used properly it has no side effects.⁸ LLLT cannot be used in individuals who: are pregnant, use a pacemaker, have congestive heart failure,

renal or hepatic disease, pulmonary edema, thrombophlebitis, deep vein thrombosis or an acute infection. As well, LLLT is not applied to the region with an artificial joint (e.g. knee replacement).^{1,3}

In cancer, LLLT is not recommended if the individual is undergoing chemotherapy or radiation therapy treatment or if they have active cancer. LLLT should not be applied over an area with active cancer or previously treated cancer.

What does the research evidence say?

We reviewed eight randomized controlled trials examining LLLT and all studies examined its use in women with breast cancer related lymphedema.^{3, 4, 9-14}

A summary of our findings

(The full findings in Table 2 can be found in the set of references online).

1 Category: Four studies compared LLLT to Sham LLLT (placebo LLLT) with or without other treatments.^{4, 9, 13, 14}

Three studies including 151 participants found no significant benefit from the LLLT when compared to sham LLLT.

One study including 50 participants found a significant benefit from LLLT for limb volume, shoulder mobility and grip strength when combined with daily exercises and compression garment use (20 hours per day). At follow-up, the LLLT group's average arm volume reduction was 23% and the sham LLLT group's was 20%.

2 Category: One study compared LLLT to no treatment.¹¹

One small study with 21 participants compared two groups: (Group 1) LLLT compared to (Group 2) no treatment.

Significant short-term benefit was found in favour LLLT for outcomes of arm volume and tissue softening; however, no benefit was seen for arm function. In the LLLT group, average arm volume reduced by 16% at 4 weeks (end of intervention) and 28% at the 8-week follow-up; whereas in the control group, average arm volume increased by 1% at 4 weeks and 5% at the 8-week follow-up.

3 Category: Three studies compared LLLT to other treatments for lymphedema.^{3, 10, 12}

One study with 50 participants compared two groups: (Group 1) LLLT to (Group 2) pneumatic compression. A significant benefit from LLLT was for arm volume (short and long-term) and for pain (long-term).

TABLE 1 – CLASSES OF LASERS 1

Laser Class	Power	Safety	Examples
1	Low, no increase in tissue temperature	Safe for eyes and skin	Barcode scanner at grocery store; Laser printers
2	Low: 1mW, no increase in tissue temperature	Safe for skin; Potential for damage to eyes (never point the laser at the eyes or look into the beam)	Laser pointers; measuring instruments; Therapeutic lasers
3R	Up to 5mW, no increase in tissue temperature	Some risk to skin if applied incorrectly; protective goggles required for eyes	Therapeutic lasers
3B	Up to 500mW	Some risk to skin if applied incorrectly; protective goggles required for eyes	Therapeutic lasers; Lasers for cosmetic purposes
4	Over 500mW	Hazardous to skin and eyes	Surgical lasers

mW: milliwatt



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Lower level laser therapy (LLLT) is believed to break down fibrotic tissue and to prevent scar adhesion to underlying healthy tissue.

One small study with 20 participants compared two groups: (Group 1) LLLT with exercise and daily use of compression sleeve to (Group 2) combined exercise and compression sleeve; however, inadequate data was provided to allow for interpretation of the findings.

One study with 46 participants compared three groups: (Group 1) LLLT, (Group 2) manual lymph drainage and (Group 3) LLLT combined with manual lymph drainage. No statistically significant differences were found between the three groups for arm volume or quality of life.

The research studies, to date, have had small numbers of participants and have used different treatment parameters, including different types and intensities of the LLLT, sizes of the limb area being treated, locations of treated points, number of treatments provided, and have differed in duration and follow-up. These differences make it difficult to compare and interpret the findings across studies.⁸

What are our conclusions on LLLT?

Currently, the evidence is inconclusive on the benefit of LLLT for breast cancer related lymphedema. Specifically:

- 1) The studies comparing LLLT to sham LLLT with or without other treatments have conflicting findings

on effectiveness.

- 2) Early evidence suggests that LLLT is not more effective than treatment with manual lymphatic drainage and compression bandaging.⁷

- 3) Early evidence suggests that LLLT may be more effective than no treatment (short term) and pneumatic compression (short and long-term).

4. More research is needed investigating the basic science of how LLLT may help to improve lymphedema.⁸

This information will help to inform the most appropriate LLLT protocol and measurement outcomes for those with lymphedema. [LP](#)



A full set of references (including Table 2: Characteristics of Included Studies) can be found at lymphedemapathways.ca

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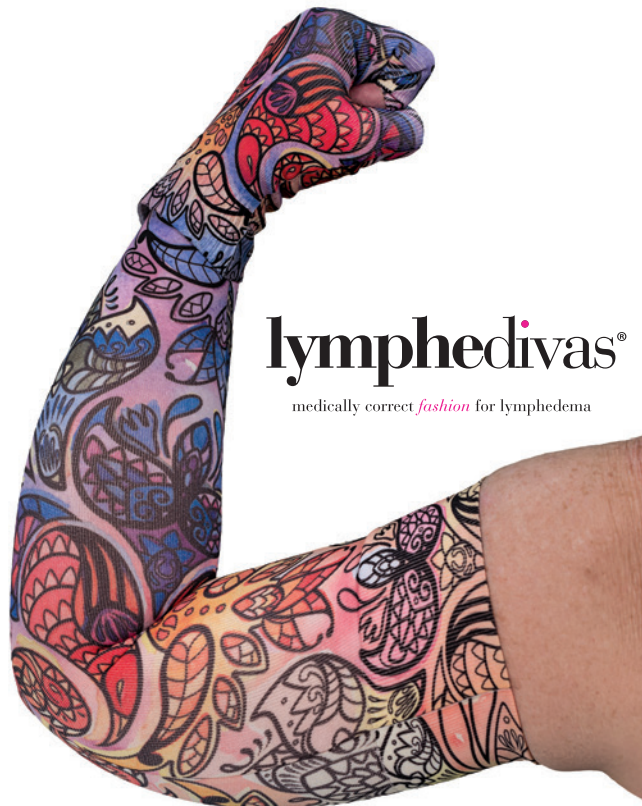
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As a nurse, I have frequently been part of a medical team that not only treats disease, but also addresses patient symptoms. Symptoms represent a departure from normal functioning or feeling, as perceived and reported by a patient, such as pain or nausea.¹ In 1999, I returned to oncology nursing after a 20 year absence. I was amazed at the many improvements in oncology symptom management that had transpired during my time away. Lymphedema, however; was still a problem, and it seemed to me that its treatment and symptom management had not improved much in 20 years.

Determined to help patients, I went to see what research was being done in the area. I found hardly anything! I learned that the current definition of lymphedema was “A condition in which fluid and protein accumulate in the extra vascular and interstitial spaces”.² While technically correct, I knew from working with patients that lymphedema was more than “fluid accumulation”. I was certain that cancer survivors with lymphedema had other “symptoms” such as achiness in their limbs and anger about having the problem; but there was no evidence in the literature to support my thoughts, or to guide me on how best to help the patients.

Symptoms can only be measured by what patients “self-report”. Symptoms are believed to have two components, their “intensity”—

Looking beyond the swelling

Lymphedema related symptoms in the spotlight

By Sheila Ridner

TABLE 1 – HIGH INTENSITY AND DISTRESS SYMPTOMS – LEG

Occurs in ≥ 80% of participants		
– Swelling	– Tightness	– Heaviness
– Appearance concerns		
Occurs in 60 – 79% of participants		
– Hardness	– Achiness	– Fatigue
– Decreased physical activity	– Inability to do hobbies	– Loss of body confidence
– Sadness		
Occurs in 40 – 59% of participants		
– Difficulty sleeping	– Decreased social activities	– Lack of confidence
– Anger	– Difficulty raising leg	– Insurance frustration
– Difficulty standing	– Less sexual activity	– Lack of self-confidence
– Flakey skin	– Pain	
Others		
– Burning pain	– Stabbing pain	– Increased appetite
– Lack of interest in sex	– Misunderstood by significant other	

how severe the symptom might be, and their “level of distress”— how much does the symptom interfere with a person’s life.³ To provide evidence about symptoms, self-report surveys/forms, scientifically designed to ensure “validity and reliability”, are required. In 1999, many such tools existed for other symptoms (e.g. pain, fatigue). Unfortunately, it quickly became obvious to me that part of the reason for the lack of evidence regarding lymphedema and related symptoms was the lack of such tools. I knew research needed to be done to develop these tools and decided that if I really wanted to help patients, then I needed to get started on that research! In fall 2000 I

became a student in the PhD of Nursing Science Program at Vanderbilt University in Nashville, Tennessee, USA.

During the last 18 years, my research team and I have worked to develop symptom assessment tools for lymphedema. Our tools capture not only the presence of a symptom, but also the related intensity and level of distress. These tools give voice to all patients experiencing swelling and related problems. They also help researchers provide evidence that clinicians can use to better assist patients. Working under the assumption that these symptoms may vary based upon location of the “swelling”, we interact with patients who have lymphedema in differing body regions. We have discovered much about how patients with and without a cancer history experience lymphedema related symptoms.

It is a pleasure to further give voice to the many patients with lymphedema who have



Dr. Sheila Ridner is the Martha Rivers Ingram Professor of Nursing at Vanderbilt University. She has conducted funded research in lymphedema and cancer survivorship for over a decade, and has numerous publications. She is well-known as an international expert in lymphedema research and for her service to the lymphedema community.

assisted us in this work by presenting some of what we have learned in this article.

Body region specific symptoms
Arm (including hands/wrists)

Several hundred breast cancer survivors with lymphedema have participated in multiple quantitative and qualitative research studies to help us better understand lymphedema in arms.^{3,7} The vast majority of these patients had Stage II lymphedema. Duration of lymphedema has been difficult to determine, as many patients were symptomatic long before receiving a formal diagnosis. As an example, in one study, the average self-reported duration of lymphedema was 50 months, but the standard deviation was 36 months, suggesting a wide variation in duration time.³ Throughout this work eight common symptoms have consistently been reported in over half of the patients: **fatigue, heaviness, tightness, difficulty sleeping, achiness, appearance concerns, decrease in physical activities and pain.** Interestingly, the most frequently occurring symptoms are not the most severe symptoms. Intensity and/or distress scores were highest in nine less common symptoms: **partners lack of sex interest, decrease in social activities, inability to do hobbies, cramping arm, increased appetite, decrease in sexual activity, lack of confidence in insurance, frustration with insurance, lack of sex interest.**

Of these symptoms, appearance concerns

TABLE 2 – FREQUENTLY REPORTED SYMPTOMS – TRUNCAL	
Decreased self confidence	Appearance concerns
Fatigue	Inability maintaining hobbies
Difficultysleeping	Decreased physical activities
Heaviness	Tightness
Less sexually attractive	Lack of interest in sex
Feeling irritated	Anxiety
Achiness	Decreased social activities
Pain	Sadness

and problems with sexual activity were the most problematic. Patients consistently told us that we were the first professionals to ask about appearance and sexuality. Few, if any, patients had ever sought counseling or support for these concerns. They suffered in silence thinking they were the only person with lymphedema who had these problems.

Leg (including ankle/foot)

Patients with lower limb lymphedema have been very helpful with our web-based research.^{8,9} Though web-based research limits the ability to examine patients to determine lymphedema stage, it provides access for many patients to participate in research who may be otherwise unable to do so. The lack of data regarding stage is an acknowledged limitation of our research. Self-reported lymphedema duration of participants across our leg studies has been as follows:

Primary LE (n=97) median=7.0 years (IQR=1.7 – 25.8)
Secondary LE (n=101) median=5.1 years (IQR=2.3 – 11.3)
Other/Unknown (n=51) median=5.7 years (IQR=1.6 – 10.8)

In our published study (n=213) that included cancer survivors with leg lymphedema (n=37) and patients with non-cancer related leg lymphedema, (n=176), most patients (>66%), experienced seven commonly occurring symptoms: **appearance concerns, heaviness, tightness, fatigue, decrease in physical activities, sadness and loss of body confidence.**

Although the number of frequently occurring symptoms in patients with lymphedema of the leg is similar to those with arm lymphedema, this group of patients appears to have many more symptoms with high levels of intensity and distress (scores ≥6 on a 10 point scale) (see Table 1 on previous page). They exact a high toll on the well-being of patients with leg lymphedema.

Truncal (including back/chest/abdomen)

Truncal lymphedema is very understudied and only recently has been recognized as a unique condition. Thus there is an absence of physical measurement methods to quantify swelling

volume and few, if any, valid staging/grading criteria. Our on-going work with patients who have truncal swelling has yielded some unexpected results. These patients report 16 symptoms that are present in greater than 50% of those in our studies (see Table 2).

Truncal swelling also has many symptoms with high intensity and/or distress levels. Notably, though experienced by very few patients with truncal swelling, difficulty moving bowels and holding urine, when present, are very troublesome. Problems with sexual activities were also severe in some cases, and undesired decreases in physical activity due to swelling also raised serious concerns.

Head and neck

The vast majority of patients who are treated for cancer of the head and neck either present with lymphedema prior to cancer treatment or develop symptomatic lymphedema within the first 18 months after cancer treatment.¹⁰ Lymphedema in this patient population has some unique features. This lymphedema presents in two ways, external swelling that is highly visible, and internal swelling that is only seen when patients have scoping procedures, and that can be quite profound.¹¹⁻¹⁷ Researchers are currently revisiting staging criteria for external lymphedema and developing internal lymphedema criteria for this population. In our first study, some patients had Stage II lymphedema with one year of cancer treatment, many more had Stage I.¹⁰ In our ongoing work with head and neck cancer patients we found many frequently occurring symptoms. Examples such as tightness, hardness, pain and fatigue are commonly reported as with other groups. However other very problematic symptoms for these patients are due to external swelling located under the chin and over the throat and internal swelling in this areas. This creates problems speaking, swallowing solids, and feeling like something is in the throat. These symptoms can compromise breathing and eating, two functions vital to life itself.

Interestingly, while these commonly occur, intensity and/or distress scores are often highest in three less frequently occurring symptoms: stabbing pain, difficulty bending over, and decreased sexual activity. Though generally not life threatening, these symptoms do impact quality of life.

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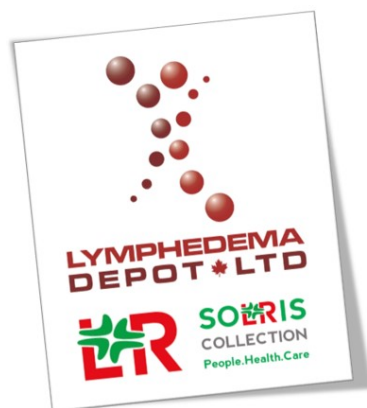
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General symptom observations

In our 18 years of work, we have yet to see a patient that had swelling without any other associated symptom. Overall, fatigue is omnipresent in most all patients with lymphedema. Many experience psychological distress that presents as sadness, anger, irritability, and frustration.¹⁸ Lower limb and truncal lymphedema appear to be highly problematic based upon the sheer number of highly intense and distressing symptoms. External and internal swelling in the head and neck area can threaten vital functions. Clearly, some of these psychological and functional problems require interventional treatment that is beyond traditional lymphedema or physical therapist's scope of service. Quality of life is impacted by lymphedema, but routine symptom assessment by healthcare providers can provide actionable information from which referrals for treatment assistance can be made.

In closing


During my 18 years working with patients, I have been blessed to collaborate with other

lymphedema symptom management champions. Jane Armer, PhD, RN; Mei Fu, PhD, RN, and Jie Deng, PhD, RN also have robust programs of research in the field. Now, when someone looks for evidence related to lymphedema, there is actually something to find! This evidence has led to an important change in the definition of lymphedema that more accurately reflects patient experience with the condition.

*"Lymphedema is a pathophysiological condition in which fluid and protein accumulate in the interstitial space. This condition contributes to the development of associated physical (e.g., pain, altered sensations, reduced function) and psychosocial (e.g., psychological distress, body image disturbance, social isolation) symptoms that requires extensive self-management."*¹⁹

Lymphedema is a multisystem disease and should be managed as such. A multidisciplinary approach to patient care is necessary. Patients with lymphedema should routinely have a thorough assessment of all body systems and be asked about their symptoms. It is especially important to evaluate the total symptom burden (number

of symptoms) and to identify high intensity/distressing symptoms that may require immediate intervention. Liberal referrals for supportive care should be made when indicated. Patients should self-advocate, reporting lymphedema related symptoms to healthcare professionals even if they are not asked about any related symptoms during healthcare visits. Additionally, self-care must extend beyond volume reduction, especially if other symptoms are present.

Though much has improved the areas of lymphedema research and treatment, much work remains to be done. For example, foundational research is needed now in the development of measurement methods and staging criteria for truncal and head and neck lymphedema. Collaborative efforts among patients, researchers, and healthcare professionals are needed to keep the momentum going! 

References plus funding and assistance acknowledgements can be found at lymphedemapathways.ca



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Profile of a Researcher: Dr. Catherine Martel

Lymphatic function and cardiovascular disease

Catherine Martel obtained a PhD in Biomedical Sciences from the Université de Montréal and pursued a postdoctoral fellowship first at Mount Sinai School of Medicine in New York (NY, USA), then at Washington University School of Medicine in St Louis (MO, USA). She is Assistant Professor at Department of Medicine, Université de Montréal, and Director of her own laboratory at the Montreal Heart Institute. Her research program focuses on the role of lymphatic vessels in the pathophysiology of cardiovascular disease.



From left to right: Carl Fortin, Maya Farhat, Catherine Martel and baby Maxence, Andreea Milasan, Ali Smaani, Gabriel Jean.

Q What prompted your interest in studying the interplay between lymphatic function and cardiovascular disease?

A I did my PhD in the laboratory of Dr. Pierre Theroux, a world-renowned cardiologist and researcher in the field of myocardial infarction (MI). When I left Montreal for my postdoctoral training in 2009, I sought to deepen my understanding of the pathophysiological mechanisms underlying atherosclerosis. Atherosclerosis is driven by the accumulation of cholesterol and immune cells in the artery wall. To gain new insights on the immunological aspect of atherosclerosis, I was pleased to join the team of Pr. Gwendalyn Randolph, one of the USA's leading scientists in immunology and former postdoctoral fellow in the laboratory of late Pr. Ralph Steinman, recipient of the 2011 Nobel Prize in Medicine. This transition allowed me to extend my own expertise in cardiology and immunology by including novel and creative ways to investigate cholesterol and immune cell trafficking out of the blood vessel wall during atherosclerosis.


High-density lipoprotein cholesterol (HDL-C) is the so-called "good cholesterol" as it transports cholesterol away from peripheral tissues such as the blood vessel wall. Epidemiological studies report a strong negative association between HDL-C and cardiovascular disease (CVD) risk in

the overall population. Thus, much effort has been directed at increasing levels of circulating HDL-C to promote the clearance of cholesterol from the atherosclerotic lesion. The subsequent clinical outcomes were, however, disappointing, revealing that more "good cholesterol" does not lead to lesion resorption nor to the prevention of CVD. In our quest to improve our comprehension of the mechanisms involved, we focused on the route that cholesterol might be taking to leave the artery wall. As the lymphatic system – lymph, from latin lymphra, meaning water – generally governs the transport of macromolecules from the tissues to the blood and, accordingly, peripheral lymph contains cholesterol acceptors, a role in cholesterol transport seemed logical. We discovered that without functional lymphatic transport, cholesterol and other components that might exacerbate the disease could not properly be cleared away from the blood vessel wall and would potentially instigate the atherosclerotic process.

Q What are you currently working on in your laboratory?

A My laboratory at the Montreal Heart Institute (MHI) is now among the very few laboratories worldwide that have direct access to the basic and clinical science tools and specialists in cardiology that would enable the characterization of the role of lymphatic vessels in atherosclerosis. The MHI is an ultra specialized hospital center dedicated to care, research, prevention, rehabilitation and to the

assessment of new technologies in cardiology. In recent studies, we provided unprecedented insight into mechanisms that are essential to clean up the blood vessel walls and thus potentially prevent the development of CVD. By using experimental mouse models either predisposed to develop atherosclerosis or protected from it, and by assessing the effect of therapies or human cells on a lymphatic endothelium in vitro, we were able to better define the prerequisite role of the lymphatic network in the prevention and treatment of atherosclerosis. More specifically, we reported that a defect in the propelling capacity of the collecting lymphatic vessels, rather than a defect in the absorptive capacity of the initial lymphatics located in the blood vessel wall, was associated to the early onset of atherosclerosis. Our results also suggest that circulating components within lymph could affect lymphatic endothelial cell integrity, which in turn would affect the clearance capacity of the lymphatic vessel per se.

The concept of modulating lymphatic transport early enough in the disease process to limit the rate and magnitude of atherosclerotic plaque progression is novel. It might help to deepen our comprehension of pathological outcomes that are not fully understood yet. Targeting and controlling specific functions of lymphatic transport could be part of the answer. 

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What are the clinical practice guidelines and why should we use them?

How International Lymphoedema Framework guidelines can change your practice By Pamela Hodgson



What criteria should I be using in my assessment of new patients? How do I know when it is most appropriate to suggest a patient transition from intensive therapy to long term self management? Are my decisions and actions in line with what is considered best practice in the management of lymphedema? If lymphedema therapists have a question, where can they turn for reliable advice amongst the many sources and sites available through the internet? The Education Working Group of the **Canadian Lymphedema Framework** suggests consulting the series of freely available documents published by the **International Lymphoedema Framework (ILF)** to help answer these questions and many others. The position documents on clinical practice guidelines (CPGs) for the management of lymphedema, 1st and 2nd editions are highlighted here.

CPGs are developed and used by many health care disciplines. They are commonly defined as: systematically developed statements of recommended best practice in a specific clinical area. Best practice guidelines are developed through a process of consensus of expert opinion and are based on current available evidence. In the case of the ILF documents, multidisciplinary clinical experts from Europe, Australia, India, Japan, Canada and the United States met to discuss and critically review the evidence and create the **ILF Best Practice Guidelines**. The first edition was published in 2006 and

the second, which focused on compression therapy, in 2012. The CPGs are designed to assist patients and health care practitioners in decision-making and provide direction to clinical care. CPGs are an invaluable tool for both experienced and inexperienced therapists to add to their clinical, experience-based expertise in clinical reasoning.


Few lymphedema therapists across Canada have the good fortune to work within a multidisciplinary team setting, the ideal for provision of optimum lymphedema care. Many others, however, work in more solitary situations, and are often the only lymphedema therapist in a community. CPGs can be very useful in aiding us in our everyday practical decision-making process, answering such questions as: how to determine the appropriate level of care for an individual patient with or at risk of lymphedema; if compression garments are unsuitable for managing a lower limb lymphedema what steps need to be taken to assess and treat this patient?

How do the guidelines work? Importantly, the ILF guidelines are based on six standards for lymphedema services. While these aims are for lymphedema care provided within an institution, the principles can certainly be applied to community-based practices. The original first three standards are: 1) identification of people at risk of or with lymphedema; 2) empowerment of people at risk of lymphedema; 3) provision of high quality clinical care that is subject to continuous improvement and

integrates community, hospital and hospice based services. The final three standards concern provision of care for cellulitis/erysipelas, compression garments and multi-agency health and social care. It is interesting to note that in many Canadian communities the lymphedema care available does not yet meet any of these six international standards.

CPGs provide definitions and detailed guidance through the use of algorithms. Clinical care algorithms are descriptions of sequential clinical decisions and interventions and are used in medicine to improve and standardize decision-making procedures, and overall care.

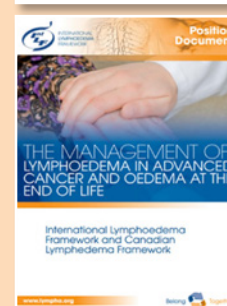
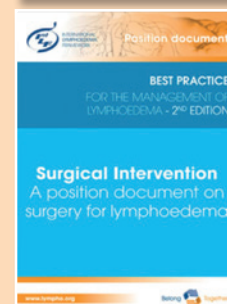
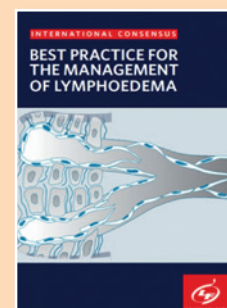
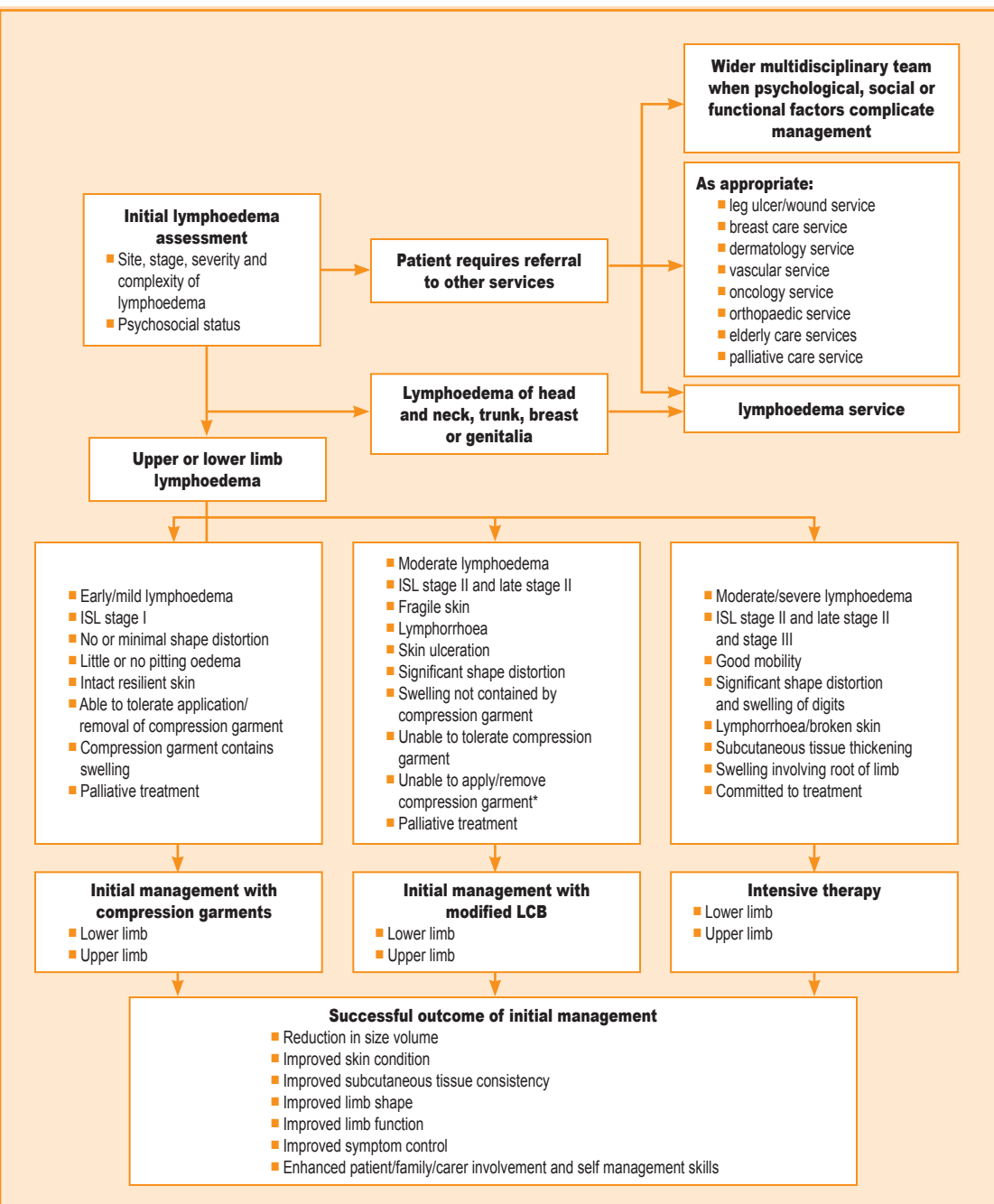
Best practice for the management of lymphedema

This 54 page document outlines all the basics of lymphedema identification, assessment, treatment and treatment decisions and provides references and appendices. It follows the **International Society of Lymphoedema (ISL)** method of staging lymphedema (stage 0 – III). For classification of severity of unilateral limb lymphedema, it uses mild (less than 20% excess volume), moderate (20-40% excess volume) severe (greater than 40% excess volume). Functional, psychosocial and pain assessment are included along with information on skin care, cellulitis, lymphatic massage, intermittent pneumatic compression, multi-layer inelastic lymphedema bandaging, and compression garments. Surgery and other treatments are briefly mentioned (a 2nd edition entitled 'Surgical Intervention' is separately available). Algorithms are given for initial, intensive, transitional and long-term management. The algorithm for the initial management of lymphoedema is reprinted here with permission from the ILF. 



Pamela Hodgson RMT, MSc, is a retired lymphedema therapist who worked in private practice in St. John's, NL then at the McGill University Health Centre Lymphedema Centre with Dr. Anna Towers, where she participated in both research and clinical care. She's been involved with the CLF since its inception.

Figure 1: Initial management of lymphoedema – (Reproduced from the Best Practice for the Management of Lymphoedema. International consensus document, with kind permission of MEP Ltd and Wounds International.



It is over a decade since the first Best Practice document was released but the decision-making models are still valid and very helpful to lymphedema therapists. Additional position statements have been produced with more information regarding management of children with lymphedema, and management of lymphedema in advanced cancer and edema at the end of life. **All publications can be downloaded for free at: <http://www.lympho.org/publications>.**



Addressing dressing

Tips to make your day easier

By Naomi Dolgoy

Our routines around clothing—dressing and undressing—are part of daily life. While getting dressed is something people do every day, the clothing that people wear varies across climates, cultures, and age ranges. While style is unique to each culture and each person, there are many considerations involved in selecting clothing and ensuring that it fits. Difficulty with clothing is something commonly reported by persons living with lymphedema, where modification, adaptation, or changes to one's way of getting dressed or the design of one's clothing items may be necessary. Creative solutions exist to help with the everyday management of donning and doffing clothing with a lymphedematous limb. Most significantly, these functional interventions can make it possible to get dressed with more independence and less difficulty, especially during times of flare-ups and compression bandaging.

Footwear

A swollen foot can be difficult to fit into a sock or shoe. While compression bandages work towards reducing edema and compression stockings maintain fluid in the foot, these decongestive treatments can be further supported with proper fitting shoes and socks.

Regardless of weather, short diabetic socks worn over compression bandaging or stockings, can be an effective way to absorb moisture, without being too tight at the ankle. In the winter, if compression stockings alone do not keep the foot warm enough, (and for those who wear open toe compression stockings), tall diabetic socks worn on top of compression garments can be helpful in keeping the foot warm without adding too much extra compression. Diabetic socks are available at most home-pharmacy stores.



Photo: Peach Couture

Please note that lymphedema patients who are also diabetic should be assessed and fitted for shoes by a professional.

When going through compression bandaging, finding a well-fitting shoe can be very challenging. In selecting daily footwear, the base of the shoe matters the most—a wider base will more effectively contain and support an edematous foot. If the shoe is too tight, it will not be comfortable to wear nor will it hold the compression bandages. A shoe with laces can be modified to fit the foot. Laces can be changed to widen a shoe, soften pressure on the top of the foot, or ease tightness in the toecap. Softer cloth shoes, such as sneakers, have much more give than leather shoes. Wide slippers, also known as diabetic slippers or edema slippers, have either an open or a closed-toe and can be adjusted for width.



The closed-toe variations can be modified by cutting out specific areas to relieve pressure spots. Wide slippers, found at most home-pharmacy stores, are also offered at some clinics and hospitals. Two companies that sell hard-to-fit shoes are Pedors and Pantera.

In the summer, supportive footwear is very important. A slide-in sandal is a good choice. Sandals with buckle or Velcro closures across the top of the foot can be useful during times of flare-ups, as extra eyelets can be created, or an extra piece of leather or fabric can be added temporarily to enable wider closures.

Many of my patients choose to wear plastic sandals or plastic clogs, for ease of donning and doffing. If these shoes become too tight, they can be cut along the top and elastic laces can be woven through the top-holes to make a laced-closure, plastic slip-on shoe. Elastic laces provide flexible support and adjustable width in a shoe. Additional modifications with elastic laces and no-tie laces make it easier to slip in and out of shoes. Modified laces are typically available at home pharmacy stores.



Naomi Dolgoy is a practicing occupational therapist, certified lymphatic therapist, and doctoral candidate in the faculty of Rehabilitation Medicine at the University of Alberta.

In the winter, a boot or shoe with a wide ankle and good traction is very important to keep the foot warm and avoid potential slipping. While a wide-based shoe may be easy to find, one that is also winter-friendly may be more difficult to locate. If the “perfect winter shoe” does not exist, there are ways to adapt or modify a shoe. Traction-aids, such as strap-on spikes, can be very helpful in winterizing the sole of a wider shoe. Since stores offer many types of traction-aids, a good idea is to try on traction-aids with specific shoes to make sure they fit. Traction-aids can be found at many different stores, including outdoor stores, sports stores, and home-pharmacy stores. The degree of traction and price of these devices also vary, but a basic model for city wear is usually less than \$30.



Bottoms: trousers, pants, underwear
Pants and underwear can feel very

constricting when dealing with a flare-up or compression bandaging in the lower body. For bottoms, a soft-elastic waistband can make donning and doffing easier. Linen or cotton pants are more breathable than are polyester pants. While tear-away track pants are easy to put on and take off, be aware of breathability and heat in synthetic fabrics when searching for pants. Most styles of pants can be modified to capri-length, with a flared hem, to avoid tightness at the ankle. As well, added closures or extra material at the waist or legs can ease management of pants over compression bandages. An extra strip of fabric sewn down the leg, either straight or wider at the top depending on the shape of the leg, can also make it easier and more comfortable to don and doff bottoms.



Photo: Byva

Rather than struggle with underwear during times of compression bandaging, disposable cloth underwear can be a good alternative.

Traction aids, such as strap-on spikes, can be very helpful in winterizing the sole of a wider shoe.



These are soft and breathable, but have high-stretch, and soft elastic, so they will not feel tight at the waist or legs. These products are usually gender-neutral and available at most home-pharmacies, clinics, or hospitals.

Tops: shirts, dresses, cover-ups

Lymphedema in an arm can affect the fit of clothing. Lymphedema in a dominant arm can also make fastening buttons, zippers, and snaps more difficult.

When selecting tops for the warmer months, choose cotton and linen fabrics that

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are more breathable and easier to modify than polyester. Exercise apparel is often designed for stretch and breathability, but be sure that the fit is roomy enough and that wrists are comfortable to avoid creating a tourniquet effect. Typically, sleeveless tops can be good as a base layer. Some shirts may need alterations for front closure zippers,



depending on the fit. Wearing an outer layer to cover the arm has more options now that more modest fashion choices are available in many stores. Large department stores often carry a beach cover-up section in addition to swimwear. These tops, robes, and dresses often have wider sleeves and bodies that work well over a lymphatic arm or trunk. Additionally, most cotton and linen long-sleeved tops can be modified by adding width to one or both sleeves. An extra swatch of fabric can be sewn along the length of the arm. Alternatively, snap closures can be added to a sleeve or to an optional extra piece, creating a “tear-away” style sleeve, whereby the extra piece can be removed or added as needed. Wide shouldered and flared sleeves, rather than fitted or tapered sleeves, can be a good choice for dressing a lymphatic arm. A bolero or non-closure shoulder cover, can be designed to match any style and provide a fashionable cover-up. The sleeves of a bolero can be made to flare slightly, creating more symmetry between the two arms and adding comfort.

Bras can be problematic, both to fit and to don. A front closure sports-bra may be an easier wear option for upper extremity or

trunk lymphedema. The straps on sports-bras are often wide and provide extra cushioning. If a more feminine style of undergarment is important, the thinner straps of a bra can be adjusted or changed and extra padding added to areas of pressure.

Closures, such as zippers, can be tricky in the back of clothing or if the pulleys are small. Try to select clothing with zippers at the front. Larger zipper sliders are easier to use, but sliders can be modified by adding a key-ring, ribbon, or colourful string to make the pull easier to accomplish independently.

Swim attire



Although swimwear can be a challenge to fit, lymphedema does not mean the end of swimming or beach days. Look for suits that do not have clasps or sharp plastic pieces, such as some decorative elements. Tankinis and one-pieces are often go-to styles in women’s swim attire. Many tailors can now modify suits for mastectomy prosthetics and for fashionable options to support a lymphatic limb. If concealing the limb is important, there are ways to create individualized swimwear options. For lymphedema in an arm, a one-sleeved design can be customized, or a swim-bolero can be fashioned for wear in the pool. Some department stores will modify suits inhouse. Some swimwear sites that customize or offer prostheses options include:

- Amoena: www.amoena.com/us-en/pocketed-swimwear
- Lands End: www.landsend.com
- Zena Swimwear: www.zenaswimwear.com

For lower extremity lymphedema, trunks and swimwear should be purchased with enough room to support changes in the limb or groin. Different styles of women’s bottoms can include skirt or longer-legged styles. Additionally, bike-shorts can sometimes be used in place of swimwear, if the fabric contains sufficient elasticity, but be aware that such fabrics can be damaged faster than normal by wetness, chemicals, and sun exposure.

Depending on the fit of a swim trunk, the mesh lining can be either helpful in containing scrotal and upper leg edema, or very uncomfortable. Mesh lining can be cut from swim trunks and a more compressing base-layer can be worn. For scrotal edema, some underwear designs include compression that can be worn in the water. These brands are often available at swimwear or sports stores. Additionally, some bike shorts can provide support under a looser fitting outer layer.

Summary

When selecting or modifying clothing, it is important to keep in mind that just because a method of dressing exists, it does not necessarily mean that the accepted way of doing things or the standard design of something is the best way of carrying out the task. Working together with occupational therapists, tailors, or clothing designers, you can create clothing options that fit your needs. There are many solutions out there to help make clothing less of a struggle and more of a style choice. **LP**



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Re: Surgery for lymphedema in Canada

Dear Editor,

In the Summer *Pathways* issue, Ms. Anna Towers brings up excellent points concerning lymphedema surgery and its limitations. Having performed lymphedema surgery for the last 13 years, I agree with her comments and underscore the conclusions.

I have found that a team-based approach with integrated lymphedema therapy is essential for the long-term success of lymphedema surgery. My experience is that such an approach, as we have published in the medical literature, can produce average volume excess reductions of 88% or more in legs and 111% or more in arms, can significantly reduce the rate of cellulitis, and can decrease the dependence on lymphedema compression garments and therapy. While the details are beyond the scope of this letter, the following points are key:

1. Patients must be carefully matched to the appropriate procedure for consistent results. For example, Vascularized Lymph Node Transfer (VLNT) and Lymphaticovenous anastomosis (LVA) surgeries alone are insufficient to produce the dramatic long-term improvements, especially in patients with Stage 2 or Stage 3 disease.
2. Integrated lymphedema therapy and Suction Assisted Protein Lipectomy (SAPL) surgery to address permanent accumulated solids are essential for optimal outcomes. Many practitioners do not appreciate that the SAPL procedure also requires specialized training and is very different from cosmetic liposuction. In addition, SAPL surgery requires integrated lymphedema therapy and compression before, during and after the surgery. It's important to note that SAPL surgery does not increase the compression garment requirement for patients with advanced lymphedema. If performed properly, SAPL makes the continuing compression requirements for such patients easier to maintain. However, staged VLNT and/or LVA procedure(s) can be performed after the chronic solids are removed by SAPL and healing is complete and may reduce the need for ongoing compression.
3. Lymphedema therapy and compression are integral parts of any successful treatment program. Lymphedema surgery is not a "magic bullet" and alone cannot produce the consistent and tremendous improvements otherwise achieved when therapy is used.

Jay W. Granzow, M.D., M.P.H., F.A.C.S.

Assistant Chief, Division of Plastic Surgery, Harbor-UCLA Medical Center
Professor of Surgery, David Geffen School of Medicine at UCL

The Summer 2018 *Pathways* is a great edition with very interesting articles. I decided to share your magazine with my colleagues (medical doctors and physiotherapists) in the Foeldi clinic. I've got so many wonderful reactions that I thought I have to share this information with you. Also the other senior consultants told me, that they don't believe there is a comparable lymphedema magazine in Germany.

You are doing an amazing good job!

Dr. Tobias Bertsch, Foeldi Clinic, Germany.

Without this magazine so many people and families would just not get the information they need. Unfortunately, the medical world is just not up-to-date on lymphedema and doesn't know how urgently it needs to be dealt with. It is a condition people need to live with for a lifetime. However lymphedema can be maintained with the practical steps you give in *Pathways* along with the knowledge you provide about lymphedema. Thanks again for producing this great magazine.

Barb Osborne, Pickering, Ontario

We would love to hear from you...

If you would like to drop us a line, please do so at:
canadalymph@live.ca

Standard treatment of care explained

By Guenter Klose



Complete Decongestive Therapy (CDT) remains the standard of care for patients with lymphedema, despite the increased number of surgeries performed on patients with lymphedema. CDT is a 2-phase therapy that consists of Manual Lymph Drainage (MLD); compression; instructions in daily exercise, skin and nail care; and general self-care. CDT is very effective in the management of lymphedema because of the interplay between the first, decongestive phase of the therapy and the second, self-care phase.

The interplay of Phase 1 and 2 of CDT.

Even though CDT is well described in the literature, there are many misconceptions about CDT. As a result, therapy recommendations and quality of care vary widely among therapy providers. With my answers to common questions, below, I hope to convey how CDT should be practiced.

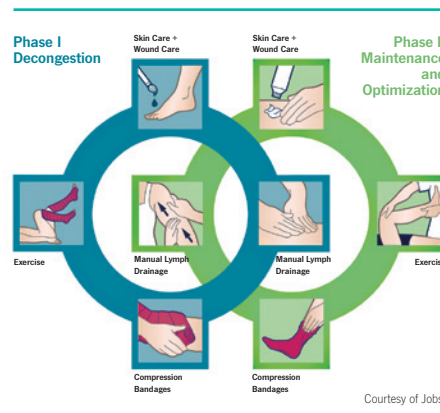
Q What is the recommended treatment frequency of CDT?

A Phase 1 of CDT is most effective when patients are treated 5 times per week for 2-3 weeks. After that, therapy visits may decrease to 2-3 sessions per week until the patient receives their custom compression garment(s) and is able to perform their daily self-care. Daily self-care (Phase 2) is imperative in order to maintain the results achieved during Phase 1 and to keep the affected area as healthy as possible.

Unfortunately, it appears to be fairly common—at least in the United States—for therapists to see their lymphedema patients only two times a week. If a patient with lymphedema is receiving therapy only two times per week during Phase 1, the treatment outcome will likely be inadequate. Therapy of only two times a week should not be called CDT.



Guenter Klose is Executive Director of Klose Training, est. 2003, which educates health professionals in lymphedema therapy through its certification courses and continuing education opportunities. Guenter received his initial training in Complete Decongestive Therapy (CDT) at the Foeldi Clinic in Germany where he returns annually to provide advanced training to lymphedema therapists.



Courtesy of Jobst

Q How does the frequency of Phase 1 CDT impact the treatment outcome?

A There are many reasons why it is beneficial to have more than two treatments per week during the initial decongestive phase. Here are some of the most important:

When skillfully applied, compression bandages will start to reduce the edema. If the bandages are not re-applied daily to adjust to the new, smaller volume, the bandages will lose their effectiveness and start to slip which might lead to the patient removing them. With no, or ineffective, compression on the affected area, the fluid will re-accumulate causing a significant slowdown of the decongestion process. Patients will have to go for therapy many more weeks compared to patients who receive CDT five times a week

and it will be difficult to transition them into an effective compression garment.

Also, a therapist who sees their patient five times a week will be better able to monitor the effect of each therapy session and make adjustments accordingly. Without several days' delay between sessions, these prompt therapeutic adjustments will speed up progress.

A faster reduction in volume will help keep patients motivated to overcome the inconvenience of daily therapy sessions and to perform their required self-care. Patients receiving only two sessions a week may experience inadequate reduction in their lymphedema which can lead to a loss of confidence in the effectiveness of the treatment and less motivation to commit to their self-care.

Q How long should each CDT session be and what should it consist of?

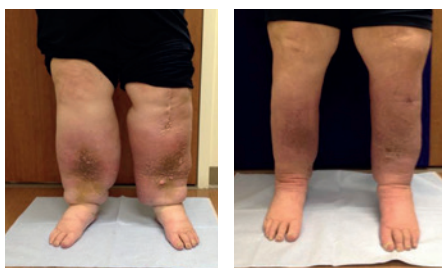
A Treatment should be a minimum of 60 minutes and consist of all components of CDT, as outlined previously. The therapist will decide on which area of the body and which component of the therapy to focus on each session. Initially, therapy should focus on truncal decongestion and patient education. In subsequent visits, the affected extremity should be decongested and any hardened (fibrotic) tissue softened to establish better tissue health and decrease the possibility of recurrent infections (cellulitis). To maximize the treatment time and subsequent outcome, patients must be on time for each session and have their compression applications ready, e.g. bandages must be clean and rolled for application after MLD.

Q Can MLD or bandaging alone be considered effective in the treatment for lymphedema?

A No. Occasionally, patients are misguided by therapy providers who shortcut the therapy by providing only individual components of CDT. Effective CDT requires the interplay of all components of CDT.

Q Does every patient with lymphedema require custom compression garments?

A No. However, most patients with lymphedema will benefit greatly from custom-made daytime and nighttime compression garments. With custom-made compression garments, the specific needs of the patient, including compression level, style, and size, can be addressed much more accurately compared to ready-to-wear garments. Custom compression garments provide better control of the lymphedema and better maintenance of tissue health, so the additional cost can be considered an investment in the patient's future health. A correctly-fitted compression




Left: Patient after receiving approximately 10 years of MLD treatment only. Right: Same patient after 3 weeks of Phase 1 CDT.

garment is as important for patients with lymphedema as the daily administration of insulin is for patients with diabetes.

Q How often does Phase 1 of CDT need to be repeated?

A Phase 1 CDT must be repeated as many times as medically necessary. It is a big misconception in lymphedema therapy that Phase 1 of CDT is a one-time process.

It is important to remember that lymphedema is a chronic and progressive condition. In contrast to other edemas, the

accumulated fluid in lymphedema is rich in protein and triggers secondary tissue changes such as fibrosis and adipose tissue deposition. These tissue changes, in turn, have a negative impact on the lymphatic vessels which are trying to compensate for the already-compromised lymphatic system. This cascade of events turns into a vicious cycle that continues to exist despite the best therapeutic approach. So, lifelong care of the lymphedema is required in order to keep the symptoms of lymphedema under control. Even with the most diligent self-care, patients with lymphedema will benefit from periodic repeats of Phase 1 CDT in order to maintain good control of their lymphedema and optimal tissue health. 

Editor's Note:

Reimbursement for this treatment protocol in its entirety is rare in Canada, requiring modification for many because of financial constraints. Provincial advocates are working hard to change this.

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My own unique colours

A patient's winning battle with negative body image

How self-acceptance and exercise changed a patient's life

By Gisele DeVarennnes

Introduction

Having Klippel Trenaunay Syndrome (KTS), a vascular malformation, and lymphedema in my right leg, I have struggled with my body image for most of my life. When I listened to Alessia Cara's song "Scars To Your Beautiful" for the first time, tears rolled down my face. It struck a chord deep inside me. The lyrics that moved me the most are: *"...Oh, she don't see the light that's shining...Deeper than the eyes can find it...Maybe we have made her blind... So she tries to cover up her pain..."*



Gisele DeVarennnes is a 48-year-old proud mom residing in Dieppe, New Brunswick and working as a Federal Public Servant. She enjoys being active, baking, knitting, reading and most importantly spending time with loved ones. She enjoys sharing her journey with others whenever she gets the opportunity.

I have covered my pain in many different ways over the years; I wore baggy clothes, so no one could see my right leg and to avoid those weird looks. I stayed away from doing things that could possibly show my leg such as wearing shorts, skirts or beachwear, sports, and even dating. I used food to hide my pain... I struggled with my weight and at one point in my life, I was morbidly obese. I never talked about it and I especially didn't want anyone touching my right leg. If I did talk about it, it was to use it as an excuse to not do something. I had built so many walls and barriers that I was existing, not living. I was negative, angry, and resentful. It consumed my life.

Luckily for me, life would give me an opportunity to change. Just like caterpillar, I would start coming out of my cocoon to discover my own unique colors. I was 41 when I got the opportunity to experience life coaching with Jim Grant. My vision, my beliefs and my thoughts would all be challenged. I realized that underneath all the negativity, anger and resentment, was a woman full of love, life, dreams and goals. I started seeing myself differently, which changed my way of thinking. I started being happier; I was a better version of myself.



Fitness coach, Cam MacKinnon.

I'm forever grateful for this challenging, but rewarding journey.

Training under the supervision of my fitness coach, Cam MacKinnon for the last six years was another golden opportunity. He would believe in me at a time when I didn't even believe in myself. He would teach me to set goals, work hard, and achieve those goals. I had many preconceived limits on what I was capable of doing fitness wise. He showed me that I was capable of doing so much more than I had ever dreamed possible. He challenged me over and over and over (and still does today) and I would not have it any other way.

With hard work, determination, commitment and consistency, the results came to fruition. My favorite example: I could barely do a 6" step-up when I started, and now I can do 21" step-ups. As I got fitter, I started losing weight and feeling better about myself, which overflowed into my everyday life both physically and mentally. There is no other place that I feel stronger both inside and out than while training with Cam. He has been a major influence in my life and I'm grateful for his guidance and faith in me.

Another huge life changing moment was learning that lymphedema could be managed. I am blessed to have an amazing certified lymphedema therapist locally.

Sophie Doiron has been amazing, and she has given me so much that words come short on how thankful I am.

I went through the initial Complete Decongestive Therapy (CDT) which drastically brought the swelling down. I felt a certain sense of normality and empowerment. It was life changing. I have maintained these results by regularly exercising,

wearing my compression garments, taking care of my skin, doing lymphatic drainage massages and becoming leaner. I am proud of the 80 pounds lost so far and I am working on attaining my goal weight. It is not easy but giving up is not an

option. It is key to managing my conditions.

I am surrounded by amazing friends and family. When I decided to start changing, they embarked on this journey

with me.

They showered me with love and support. I could not have done it without them. They have listened to me, given me a shoulder to cry on, celebrated with me, laughed with me and stood beside me through all these changes. I am living my life to the fullest. I am happier than I have ever been. I refuse to hide anymore. Life is too

short. Not everyone is comfortable with my leg and I still get weird looks. The difference is—I'm not as angry anymore.

I don't let it consume me or stop me from doing things. I let the tears flow when they



I realized that underneath all the negativity, anger and resentment, was a woman full of love, life, dreams and goals.

need to, wipe them dry and continue on my journey. Instead of considering myself a freak, I consider myself unique. A unique piece of artwork is priceless, and so am I.

Do I have it all figured out today? No, but I have come a long way. I am proud of myself and I am celebrating the journey that I have travelled. I will continue to work hard towards becoming the beautiful, unique butterfly I was always meant to be. Someone who is very near and dear to my heart keeps repeating the following: How do you eat an elephant? One bite at a time. Small changes turn into amazing transformation over time. [LP](#)



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Hints and Tips

Skin care

Patients with lymphedema may experience intermittent leaking of fluid from the affected limb, especially with primary leg lymphedema. This leaking of fluid is called lymphorrhea and can be very hard on the skin. Using a highly absorptive product for drainage is important. This may include gauze made with calcium alginate or even incontinence pads. Use a protective



barrier cream or spray to protect the skin. Compliance with compression therapy is essential to preventing and treating lymphorrhea.

See your doctor or nurse practitioner if you develop a fever, pain, heat and redness in the skin. It may be cellulitis and always requires medical attention.

Jean Ann Ryan, RN BN, St. John's, NL

If the shoe fits


People living with lymphedema know that fitting shoes can be a problem when one foot is swollen and larger than the other. It is expensive to purchase duplicate pairs of shoes in different sizes, so purchase



the shoe size that will accommodate the larger foot. An insole can be used to down-size the shoe for the "normal" foot. You can keep the insole in your bag so that you can either insert or remove it when your foot fluctuates during the day or when travelling.

"Best" size self-bandaging

If you have some pitting edema (where pressure on the limb with a fingertip leaves an indentation), self-bandaging at night or 24/24 for a few days or more when you

are due to replace your garment may lead to better control of your lymphedema. As a compression garment gets older the limb size might increase. Self-bandaging is to try to get back to your "best" size. There are many new self-bandaging aids and devices on the market. For more severe degrees of pitting edema, repeat a shorter course of decongestive lymphatic therapy with your therapist prior to a garment change. 



Dr. Anna Towers, Montreal, QC

Send us your hints and tips.

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Lymphedema surgery: State of the art

Lymphedema surgery, when integrated into a lymphedema treatment program, can provide more effective and long-term improvements than non-surgical treatments alone and can provide significant improvement for issues such as: recurring cellulitis infections, inability to wear clothing appropriate for the rest of their body size and loss of function of arm or leg. Surgical treatments should not be seen as a “quick fix”, and should be pursued in the framework of continuing lymphedema therapy and treatment to optimize each patient’s outcome. When performed by an experienced lymphedema surgeon as part of an integrated system with expert lymphedema therapy, safe, consistent and long-term improvements can be achieved. Source: *Clin Exp Metastasis*. 2018 Jul 06



Patient expectations of lymphedema surgery

Patients with lymphedema often have unrealistic expectations for lymphedema surgery. The research data of this study suggests that many patients learn about lymphedema surgery from nonphysicians, with many expecting complete or significant improvement of lymphedema associated symptoms with surgery. Findings emphasize the importance of addressing patient expectations and providing appropriate

counselling before surgery. Source: *Plast Reconstr Surg*. 2018 June; 141(6):1550-1557

Meaning of success

The goals of treatment can be different for the therapist or for the person who lives with lymphedema. The aims of one study by Prof. Jane Arner and Dorit Tidhar were to understand what people with lymphedema consider to be the meaning of success in the intensive phase and in the long-term phase of lymphedema management. The most common themes that emerged from the data were hope; lack of clarity as to moving to the long-term phase of treatment; and empowerment and maintenance versus back to normal (acceptance versus hope). Conclusion: In the intensive phase of treatment, success means disappearance or improvement of the swelling and pain, and better function. In the maintenance phase, success was deemed as stability and not getting worse, but also, for some participants, disappearance of the swelling. Source: *Journal of Lymphoedema*: Jun 2018



randomly into two groups: group I (stem cell therapy group) and group II (control group). In group I, there was a decrease in the mean circumference at ankle after 6 months, which was statistically significant ($t=3.250$, $p=0.014$). This was associated with marked improvement of pain and walking ability. Whereas in group II, the change in the circumference was statistically insignificant ($t=1256$, $p=0.349$) with no satisfactory pain relief nor improvement in walking ability. Biopsies showed marked increase in the number of lymphatic capillaries in group I. Stem cell therapy can achieve improvement in limb circumference as well as pain relief and improvement in walking ability in patients with chronic lymphedema compared with those in control group. Source: *Lymphat Res Biol*. 2018 Jun;16 (3):270-277

International Lymphoedema Conference

The recent international conference in Rotterdam, the Netherlands was a huge success. 628 participants from 44 countries listened to key opinion experts from around the world. In addition to the key note address on health economics, featured topics included obesity, diagnosis, surgery, lipedema etc. For a copy of the detailed program and submitted abstracts, visit www.2018ilf.org.



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May 17-19th, 2019
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The Australasian Lymphedema Association will host the **2019 ALA Symposium** in Sydney, Australia. Their 3-day program will feature a whole day plenary session, workshops, social events and more. ■ www.lymphoedema.org.au

May 30 - June 1, 2019
Austin, Texas

The Lymphatic Forum 2019, Exploring the Lymphatic Continuum is hosted by Texas A&M University, and will feature world-renowned speakers. ■ www.navbo.org/events/lymphatic-2019

June 13-16, 2019
Chicago, USA

SAVE THE DATE. International Lymphoedema Framework (ILF) Conference, cohosted by the American Lymphedema Framework Project. This event will be held at the Hyatt Regency in downtown Chicago. Call for Abstracts opens October 1. Check the website for more details. ■ www.lympho.org

2019 Dates
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Training and Certification Programs. Courses are offered by various educational schools for qualifying healthcare professionals. Some provincial lymphedema associations also organize or host educational courses. We encourage you to refer to the websites of our advertisers and the individual provincial associations for specific dates and locations.

You Are Not Alone

You have access to information, resources, contacts and support from people who know what you're going through from their own personal experience. You have the following organizations on your side.



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Atlantic Region: Atlantic Clinical Lymphedema Network	www.atlanticallymph.ca
British Columbia: BC Lymphedema Association	www.bclymph.org
Manitoba: Lymphedema Association of Manitoba	www.lymphmanitoba.ca
Newfoundland and Labrador: Lymphedema Association of Newfoundland and Labrador	www.lymphnl.com
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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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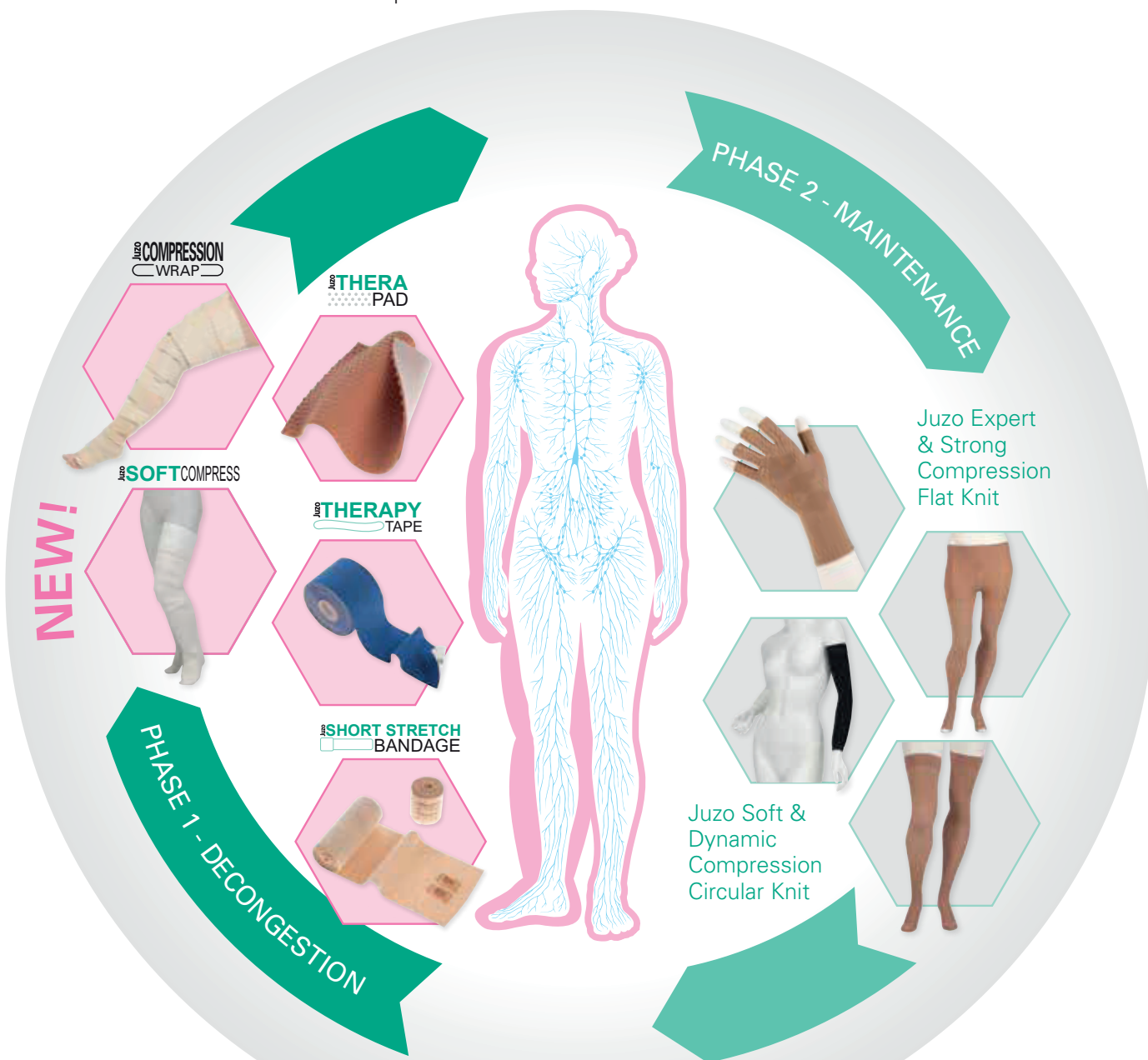
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