

Canada's Lymphedema Magazine

Pathways

Empowering patients and professionals

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WINTER 2017/18

Nordic
Walking

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NOUVEAU...

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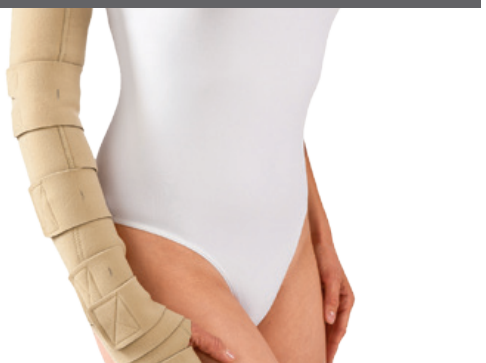
**NOUVELLES
COULEURS
ET TENDANCES
DES TRICOTS
À PLAT MEDI**

**COMPLETE THERAPY CONCEPT FOR ALL PHASES OF LYMPHEDEMA
CONCEPT DE THÉRAPIE COMPLÈTE POUR TOUTES LES PHASES DU LYMPHOÈDÈME**

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CIRCAID JUXTAFIT PREMIUM



New year, same goals

Persistence is key when it comes to influencing policy changes

Despite the newest estimation of the number of people in Canada living with lymphedema/chronic edema to be one million, lymphedema remains under-recognized, under-diagnosed and under-treated. This is true not only in Canada, but around the world. Stuart Nairn from Nottingham University in London, England provides us with a sociologist's perspective of why lymphedema may have such a low status in the world of diseases. His viewpoint helps us understand why this is so and what must be done to change the paradigm; his final point emphasizes that patient pressure is necessary to influence policy leaders.

The National Lymphedema Conference was a huge success, with extremely positive feedback from exhibitors, sponsors, speakers and delegates.

This exact topic was the focus of a special half-day session at the recent national lymphedema conference, where 12 leaders representing the provincial lymphedema associations across Canada, discussed how they could align their efforts to pressure local policy leaders for better reimbursement of lymphedema care. It was especially exciting to have the new Lymphedema Association of Nova Scotia taking part. Uniting voices and sharing best practices is an important step to addressing the inequities of lymphedema care in Canada.

The National Lymphedema Conference, held in Montreal this fall, was a huge success, with extremely positive feedback from exhibitors, sponsors, speakers and delegates. A total of 376 participants



Conference scientific and organizing committee members: (left to right): Dr. Anna Towers, Rachel Pritzker, Robert Kilgour, Anna Kennedy, Dr. David Keast and Margie McNeely.

attended over the two days with 98% of participants stating that the conference was a worthwhile investment of their time and money. A special thanks to both Shirin Shallwani (pictured right) and Anne-Marie Joncas, who were both kind enough to share their reviews of the conference.

Dr. David Keast and Prof. Christine Moffatt introduced a debate about lymphedema vs. chronic edema during the opening Friday plenary session. We include a reprint from the *Journal of Lymphoedema* that gives you some additional points to consider on this topic. You will see that definitions are not clear-cut and that ongoing discussion can be healthy for understanding this complex problem.

The consistently popular "Panel of Experts" session that closed out the conference provided an opportunity to address pertinent questions. We share some of the transcribed questions and answers in this issue. Remaining discussion regarding surgical solutions will be published in our subsequent, Spring 2018 issue.

Exercise continues to be an important component of lymphedema self-care and so we are pleased to

share two articles, which emphasize different exercise perspectives. Chantal Turgeon, (pictured on the cover), a certified lymphedema

therapist, explains how Nordic walking adapted for lymphedema can be beneficial for self-management and Kathleen Woudzia provides an inspirational perspective of how exercise has helped her feel in control of her lymphedema.

Final survey results are not yet in—but so far, our readers are telling us that the personal patient stories included in *Pathways* are one of the most read and important components of the magazine. Stay tuned for the full *Pathways* readers survey results, which will be published in the Spring issue. In the meantime, we hope you enjoy reading this issue and will pass it on to another patient or health professional, who can learn more about lymphedema. [LP](#)



Anna Kennedy

Canada's Lymphedema Magazine

Pathways

Empowering patients and professionals

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Lymphedema: A sociological analysis

Why lymphedema struggles for the spotlight in healthcare systems

By Stuart Nairn

Health care systems should be designed to meet peoples' health care needs and so, should maximize health and minimize suffering. Unfortunately, the practical application of this apparently simple statement is not so simple. Apart from the complex nature of illnesses, the biological processes involved, and the available treatment regimes, there are many other factors that contribute to the evolution and development of a health care system. Influential factors include the social, economic, cultural, political and institutional processes at work in any society. The conditions that gain attention are not directly based upon needs. For example, tuberculosis has traditionally had a low profile, but there is extensive literature on the treatment of tropical diseases.¹

Sociologists have been particularly preoccupied by these types of issues and are concerned with why certain social groups gain

more attention, have more status, and can influence policy more than others.² Lymphedema is an interesting case that illustrates the complexity and problems associated with the politics of health care. It is convincingly argued that lymphedema is an undervalued and undertreated condition³. This article examines why this might be the case.

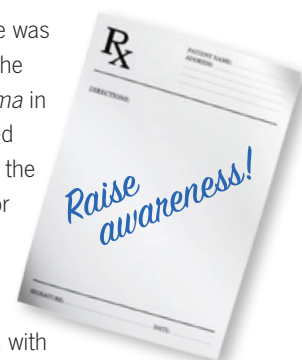
People with lymphedema face a number of problems in accessing resources for care which include: the problem of diagnosis, the scientific interest in the topic, the nature of the interventions (nurse or therapist led), the cultural status of lymphedema, the economics of research and the policy dynamic of managing chronic conditions.

The problem of diagnosis

Diagnosis reflects more than simply determining an underlying biological problem. Many different mechanisms are involved in constructing a diagnosis. In the field of

lymphedema, this issue was usefully highlighted in the *Journal of Lymphoedema* in an article that discussed whether we should use the term chronic oedema or lymphedema, or even phlebo-lymphoedema.⁴

The authors of this debate were concerned with two aspects. Firstly, how accurately does the language reflect the symptoms and underlying pathology and secondly, how does the definition contribute to the profile of the condition? While "chronic oedema" might be more accurate, it could be confusing to policy makers. The issue here is that diagnosis has an administrative function; health care systems provide a package of care about what is a known and clearly defined problem.⁵ Managers need to know how prevalent (common) the condition is. Prevalence can only be measured when clearly defined, and when the epidemiological data supports the provision of resources. Clarifying the diagnosis is therefore central to the profile of an illness category.



Stuart Nairn PhD MA RGN, is a Lecturer in adult nursing at the University of Nottingham in England and has a particular interest in sociological and policy aspects of health care.

Insurance-based systems often have problems incorporating lymphedema into a package of care.

Scientific interest

Different sciences have higher status than others, and within different sub fields some are considered more important than others. For example, the high status of genetic science is related to its reputation as “big science” but the evidence of its effect on health care is less impressive⁶. Despite the efficacy of many treatments for lymphedema, the science underpinning it is not seen as appealing. Album and Westin⁷ researched the attitudes of physicians and medical students and found that they associated more prestige with surgical specialities such as neurosurgery and thoracic surgery, while geriatrics, psychiatry and rheumatology had a low prestige. From educational values through to clinical practice, the acute and the surgical are nearly always accorded more value than the elderly with chronic conditions who require a more holistic and multi-faceted set of interventions. In general: clear-cut surgical and pharmacological interventions are seen to be more valuable.

Social status

The professional group responsible for delivering care can also affect the status of an illness. Sociologists have identified the issues around professional power. The medical profession has generally had a major influence on resource distribution.⁸ A significant portion of the care (compression bandaging, skin care, exercise and massage) required for lymphedema patients is primarily administered by nurses or physiotherapists. These are not high

technology interventions, but their efficacy, when appropriately carried out, can make a significant difference to people's lives.

Embarrassing bodies

There is an aesthetic to different illnesses. Problems that manifest on the skin or which are visually unattractive can create a stigmatising context for illness.⁹ A systematic review on the psychosocial impact of lymphedema showed that it had a significant effect on people's sense of wellbeing, can generate emotional disturbance and cause psychological distress. The consequences of this can often lead to isolation, perceived social abandonment, problems at work and public insensitivity.¹⁰ Furthermore, media stories and fictional programs have played a role in enhancing the status of some specialities. Emergency care was a medical backwater, but due to its heroic and visually attractive media aesthetic has managed to raise its profile in the policy context.¹¹ It is clear that lymphedema does not have the same influence.



Economic and policy issues


Due to some of the problems mentioned above, resourcing care is an increasing challenge. For example,

insurance-based systems often have problems incorporating lymphedema into a package of care. Furthermore, many of the costs of care become hidden; loss of income from sickness, mental health issues and quality of life issues undermine people's ability to engage in the social world. In addition, many lymphedema patients are hidden from view in community and nursing homes, often making them difficult to capture in the statistics. The

obvious signifiers of pressures for some specialities, such as lack of beds, increased waiting times for operations or patients sitting on stretchers in the corridors of emergency departments are not so obviously represented in a chronic condition that is often diffusely spread throughout the community and is therefore less likely to gain attention.

Implication for policy

Lymphedema confronts a number of challenges in accessing the attention of policy makers and health professionals. In short, it has a low status and therefore struggles to gain the requisite resources to meet the real needs of patients. Health care increasingly operates in a competitive environment, with many groups with their own priorities trying to have their voices heard. While the ideal situation would entail a proper evaluation of needs, this is not the only criteria for the delivery of care.¹² Politics, economics and the ability to raise the profile of an illness all play a part in the provision of care. The following strategies might be suggested to enhance the situation of lymphedema:

- 1 **More research on prevalence based on a clear definition of the underlying pathology.**
- 2 **Improved knowledge and skills for health care professional based on evidence based guidelines.**
- 3 **More research on the economic costs of undertreating lymphedema.**
- 4 **Political pressure from patient groups and health professional on policy makers.** 

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

Editor's Note:

The International Lymphoedema Framework is undertaking several projects that incorporate all four of these strategies. Stay tuned for future reports on the LIMPRINT prevalence study, Lymphorac (economic impact), Lymphedema Education Benchmark Standards and the Outcomes Measures Projects.

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2017 Conference highlights

National Lymphedema Conference, Montreal

Canada's first national bilingual lymphedema conference

By Shirin Shallwani

Co-hosted by the Canadian Lymphedema Framework and the Lymphedema Association of Quebec, the 2017 National Lymphedema Conference welcomed over 376 people at the Omni Hotel Mont-Royal in Montreal, Quebec (October 27-28, 2017). Truly representing the diversity of lymphedema, the conference participants included patients directly affected by lymphedema and their supporters, lymphedema therapists, garment fitters, health professionals and research scientists. Throughout the two-day conference, the venue rooms and hallways were bustling with participants energetic and engaged in learning and conversation. From the welcoming registration process, to the stimulating plenary and breakout sessions, to the interactive opportunities with the exhibitors and associations, the conference was well organized, was extremely informative and offered a unique and special experience for everyone.

Conference program

The overall theme of the conference was focused on chronic edema and lymphedema as "a growing problem in Canada". The agenda was jam-packed with professional education sessions, practical and informative workshops, research seminars and collaborative opportunities. Over and above the main conference program, additional opportunities included industry-sponsored practical workshops on compression techniques, a full-day course on lymphedema management for community nurses provided by **Dr. Anna Towers** and **Robert Harris**, a specialized half-day workshop on pediatric lymphedema given by



Dr. Isabelle Quéré and **Dr. Catherine McCuaig**, as well as a meeting for provincial lymphedema association leaders. The Saturday lunch options included a pediatric lymphedema networking event, patient perspective sessions and a roundtable discussion on hospital clinics.

Plenary sessions

The plenary sessions were delivered by national and international keynote speakers



Shirin Shallwani is a physiotherapist and certified lymphedema therapist specialized in cancer rehabilitation. She is currently pursuing her doctoral studies at the University of Ottawa School of Rehabilitation Sciences and is involved with clinical research at the McGill University Health Centre Lymphedema Program.



and revolved around clarifying terminology related to edema, understanding the prevalence of lymphedema, addressing obesity in this population and exploring novel treatment approaches. An expert panel at the end of the conference permitted interactive opportunities for questioning and discussion with international leading specialists in lymphedema.

Chronic edema and lymphedema:

In their engaging and thought-provoking session, **Prof. Christine Moffatt** and **Dr. David Keast** highlighted the need for clarity and consistency in the use of terminology related to edema. Lymphedema has been defined as an abnormal accumulation of protein-rich lymph fluid caused by lymphatic malformation or damage (International Lymphoedema Framework, 2006). Unfortunately, there remains a general lack of awareness related to the diagnosis and treatment of lymphedema as well as a misconception that lymphedema only occurs after cancer, or specifically breast cancer.

Furthermore, the changing demographics of the global population, such as ageing, increased comorbidities (e.g. chronic venous disorders), reduced mobility and higher levels of obesity, may be contributing to the rise worldwide in cases of chronic edema, including lymphedema. The term “chronic edema” has been used to describe edema present for at least three months that does not subside with elevation and is associated with at least one skin or subcutaneous change (National Lymphoedema Partnership, 2015). This umbrella term recognizes a wide range of different causes, mechanisms and risk factors resulting in long-term swelling, the majority of which likely have a component of lymphatic involvement. Thus, chronic edema and lymphedema are not exclusive terms and lymphedema is an important part of the wide spectrum of chronic edema. The speakers highlighted that “chronic edema” is not a diagnosis in itself but a public health term that may assist key stakeholders in adopting a common language and result in a better understanding of the extent and impact of this heterogeneous problem. Moreover, embracing the use of such an inclusive term may improve the timely and appropriate diagnosis of various conditions associated with chronic edema and lymphedema, as well as enhance equitable access to tailored treatment options, such as compression therapy, for different segments of the affected population.

Lymphedema prevalence in Canada:

Understanding the prevalence of lymphedema, that is the number of people living with lymphedema, can shed light on the magnitude of the problem.



In their eye-opening presentation, national lymphedema experts **Dr. Keast** and **Dr. Towers** spoke about the challenges with measuring these figures, such as the limited awareness about lymphedema within the medical community and the public, as well as the lack of standardized methods

for diagnosis and early detection. Focusing on the Canadian level, they presented estimated figures calculated on published rates of primary lymphedema, cancer-related lymphedema and other co-existing conditions, such as obesity and mobility disorders (Keast & Towers, 2017). According to their analysis, it is estimated there are currently at least one million people living with lymphedema in Canada. Of these, about 150,000 cases are likely due to cancer, while more than half are considered related to morbid obesity. Despite the limited research on Canadian cases of lymphedema, recent studies have consistently demonstrated the association between non-cancer-related lymphedema and cellulitis infection, a potentially serious complication requiring immediate medical care. These findings highlight the severity and impact of lymphedema on Canadians and their health care system and demonstrate an urgent need to improve the awareness and management



of lymphedema in Canada.

LIMPRINT study:

Another exciting development in the area of lymphedema research at the

international level is the LIMPRINT study. As explained by **Prof. Moffatt**, chair of the International Lymphoedema Framework, this initiative is based on an international partnership and the purpose of this project is to “develop and validate an international prevalence methodology”. The goals of this work are to facilitate the assessment of the prevalence and impact of lymphedema worldwide and to demonstrate that chronic edema and lymphedema are part of a major global issue. Components of this tool include a core section, a clinical assessment, and specific modules (e.g. to assess disability, quality of life, swelling, etc.). This collaborative project involves 40 sites located in 9 countries with data collected on more than 13,000 participants. Preliminary analyses on this dataset revealed that the majority of people with lymphedema were female (71%) and had secondary lymphedema (84%), 16% of the cases had wound issues in addition to

It is estimated there are currently at least one million people living with lymphedema in Canada.

lymphedema and 34% were also obese. Interestingly, worse quality of life was reported in males and in people with wounds, morbid obesity and history of cellulitis. Many cases of edema were actually non-cancer-related and were commonly discovered in people with co-existing conditions within different settings, including both hospital and community sites. These results further emphasize the need to acknowledge lymphedema as a wider problem beyond cancer and consider its burden on patients, health care systems and societies in general.

Obesity and lymphedema: A common link between obesity and lymphedema is becoming increasingly recognized and,

in light of the global rise in obesity rates, understanding and addressing obesity are important aspects of lymphedema management. As **Dr. Tobias Bertsch** explained, despite the popular belief that obesity is simply caused by poor diet and low physical activity, multiple factors may actually be related to obesity, including genetics, epigenetics as well as biological, socio-cultural and psychosocial factors. During his dynamic presentation, he expanded on the pathophysiological



connection between obesity and lymphedema, where fat (adipose) tissue can influence lymphatic contractility and lymphedema can further induce changes in adipose tissue. Thus, a reciprocal relationship between the two conditions appears to exist. Furthermore, obesity has been identified as both a cause and a risk factor for the development of lymphedema.

With respect to weight loss strategies,

strict diets and exercise programs have been most commonly reported. However, weight loss diets have not been found to be very effective in the long-term, with research suggesting 95% of people regain their weight within 3 years. Moreover, while exercise has numerous health benefits, a tremendous amount of physical activity is required to burn adequate calories for actual weight loss. With extensive clinical experience as a specialized physician at the Foeldi clinic in Germany, Dr. Bertsch provided general direction on how to address obesity in the context of lymphedema care. The first step is a change of attitude towards patients suffering from obesity. Recognizing the multiple factors associated with obesity and removing the blame from the patient can help reduce the stigmatization that commonly occurs with obesity. Secondly, a shift towards appropriate therapeutic goals, such as weight maintenance or stabilization of weight gain instead of weight loss, is needed. A treatment focus on individual wellbeing and healthy lifestyle practices (including the consumption of non-processed foods, the avoidance of sugar and the incorporation of daily activity) may be helpful in supporting this population. Finally, in some cases, bariatric surgery may also be considered in collaboration with a



multidisciplinary team approach to enhance long-term outcomes. This session provided valuable information and strategies to manage obesity in lymphedema practice.

Surgical techniques: With the emergence of novel treatment approaches in the management of lymphedema, **Dr. Alex Munnoch**, a highly specialized consultant plastic surgeon from Scotland, spoke about the evolution of specific surgical techniques: lymphaticovenous anastomosis, lymph node transfer or graft, lymph node transplantation, axillary scar release and liposuction. Based on his review of the literature and clinical experience, he reported positive outcomes in limb volume and quality of life after liposuction for a number of cases of lymphedema. However, Dr. Munnoch reminded us that this particular surgical procedure removes the bulk of the fatty tissue and does not treat the underlying condition of lymphatic damage or abnormality, typically resulting in the need for ongoing compression therapy. Moreover, the eligibility for such procedures depends on a range of considerations including the original cause of lymphedema, the availability of a specialized plastic surgeon and a multidisciplinary team (including a lymphedema therapist)

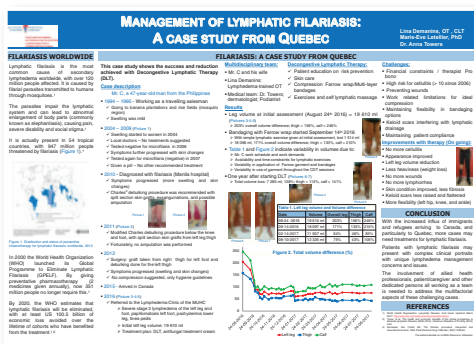
for long-term care, the adherence of the patient with previous decongestive therapy and ongoing compression as well as the risk of post-operative complications, such as infection and nerve damage. Nonetheless, as noted in this interesting session, the progress made in surgical procedures for lymphedema is exciting and such techniques may be beneficial for selected cases of lymphedema.

Concurrent sessions

A broad range of topics was covered within the concurrent sessions and targeted different groups of participants attending the conference. One important area of focus was the assessment of lymphedema and its impact through the use of patient-reported instruments, such as the recently developed Lymphedema Symptom Intensity and Distress Survey measures, as well as objective assessment techniques, such as ultrasonography. **Dr. Robert Kilgour** reported on physiological changes at the levels of the skin, subcutaneous fatty tissues and skeletal muscles in the presence of lymphedema. **Dr. Sheila Ridner** discussed the significant impact of lymphedema on



Congratulations to the winners of the poster presentations.



1st prize winner (and recipient of \$400.00): Lina Demanis, a CDT therapist from Montreal, Quebec. Her poster was entitled “Management of Lymphatic Filariasis: A case study from Quebec”.

2nd prize winning poster: “Decongestive Resistance Exercise with Advanced Compression for Breast Cancer Related Lymphedema Management (DREAM): A Protocol for a Randomized Controlled Trial”. M. Al Onazi and M. McNeely. The prize of a complimentary registration to the next lymphedema conference was awarded to Mona Al Onazi from Edmonton, Alberta.



(Left to right): Lina Demanis, 1st prize winner of the poster competition, Anna Kennedy, conference co-host and Dr. Anna Towers, scientific committee co-chair.

Honourable mention poster: “Effects of Targeted Exercise Program on Time

Course of Upper Limb Function Post Radiotherapy in Young Adults with Breast Cancer: A Pilot Randomized Control Trial”. M. Ibrahim, T. Muanza, N. Smirnow, W. Sateren, B. Fournier, P. Kavan, M. Palumbo, R. Dalfen, M.A. Dalzell. The prize of \$150.00 was given to Marize Ibrahim, from Montreal, Quebec.

Peoples Choice award: “Is a 90-Minute Weekly Water-Based Exercise Enough to Control Swelling in Gynecological Cancer Survivors Living with Secondary Lymphedema?” An Indigo gift card was awarded to Azlak Tarig from Montreal, Quebec.

patient wellbeing and functioning, as well as frequent concerns related to resources (e.g. insurance coverage) within this population.

Advances in treatment options, including innovative compression systems, skin care practices, psychological strategies as well as remedial and other exercise techniques (e.g. yoga and Tai chi), were also explored through various educational and practical forums. There was an emphasis on addressing the unique concerns of special populations, such as patients with pediatric lymphedema, lipedema and wound issues. [LP](#)



Conference abstracts and references can be found at www.canadalymph.ca.

Conference Summary

Key messages from conference sessions

- **“Chronic edema”** is not a diagnosis in itself but a public health term that may assist key stakeholders in adopting a common language and result in a better understanding of the extent and impact of this heterogeneous problem.
- It is estimated there are currently **one million people living with lymphedema in Canada**.
- **The LIMPRINT study** is a collaborative initiative to develop and validate an international prevalence methodology that may facilitate the assessment of the prevalence and impact of lymphedema worldwide.
- A reciprocal relationship between obesity and lymphedema has been recognized. **Addressing obesity in lymphedema management requires a shift in attitudes and therapeutic goals** and the consideration of multi-disciplinary and multi-modal approaches.
- **Surgical techniques**, such as liposuction, may be a promising treatment option for selected cases of lymphedema.
- Current work in lymphedema is **exploring patient-reported and objective assessment tools, innovative treatment approaches and special populations** (e.g. pediatric, lipedema and wounds).



Rachel Pritzker,
conference co-host.

The 2017 National Lymphedema Conference brought together people directly affected by lymphedema, health professionals, researchers, industry and policy makers to work towards the common objective of improving the care of people with or at risk of lymphedema. This event facilitated unique opportunities for learning, dialogue and networking and proved to be a productive forum enabling future progress in the field. Congratulations and much gratitude to the organizing and scientific committees, the Canadian Lymphedema Framework and the Lymphedema Association of Quebec, the sponsors, the exhibitors and the hardworking volunteers who dedicated endless energy, time and resources to ensure the success of this event!

2017 National Lymphedema Conference

The conference success would not have been possible without the generosity of our many supporters, who donate their money or time and who support our passion for furthering lymphedema education and awareness.



With additional funding provided by:

Palliative Care McGill, Tourism Montreal, University of Montreal, Quebec Ministry of Health and Social Services, and the Department of Canadian Heritage.

Lymphedema Conference

Experiencing the future of lymphedema

By Anne-Marie Joncas

I've had arm lymphedema for two years now and have already attended two lymphedema conferences. Such events give attendees the equivalent of an advanced college education with an added human dimension. At the **National Lymphedema Conference (Montreal, Oct 27-28, 2017)**, participants nourished their minds as well as their souls with the art of managing lymphedema.

As a patient, participating in the conference gave me an ideal opportunity to see and touch the latest pressure garments and devices made by the major manufacturers.

I will certainly have plenty to talk about when I next see my compression garment fitter! One company took a photo of my hand with a digital imaging device that optimizes the accuracy of measurements to custom fit gauntlets. The effectiveness of this technology could ensure made-to-measure garments fit better from the outset.

Conference participants got a chance to enlighten themselves amidst truly inspiring people. I attended two important, patient-oriented lectures. The first was given by Montreal dermatologist, **Dr. Nicole Paquette**, and her nurse colleague, **Mélanie Poitras**. Together, they explained that skin care is crucial for lymphedema patients.

We were shown photos of cellulitis, a common infection for lymphedema patients, along with the full table of anti-biotherapy recommended by the International Lymphedema Framework. For Dr. Paquette,

whenever cellulitis is suspected, the approach is clear: due to the greater risk associated with lymphedema, it is best to treat it quickly with antibiotics even if this later proves unnecessary. Patients who had already experienced cellulitis asked clear and pertinent questions which revealed their anxiety about the serious complications that can ensue. They wanted to know the tell-tale signs that indicate consultation is necessary and where to go for prompt treatment, whom to consult for the right antibiotic, how one can be sure of getting the right medication and whether a patient who has already had cellulitis can keep a prescription on hand in the event of an emergency. Not only did these questions reveal the overall lack of resources, knowledge and direction that currently make it difficult for patients to avoid complications, they also emphasized the need for better support.

I found the lecture by **Dr. Marc Hamel**, oncology psychologist at the McGill University Health Centre, extremely valuable. He described how lymphedema patients are affected by many feelings: depression and non-acceptance, of unfairness and of being ignored by medicine and research communities, fear of being a burden to others, and of social isolation. Their coping mechanisms are overburdened by a chronic condition and they experience everyday difficulties in getting around, reduced mobility, sleep disorders, depreciated self-image, a disrupted sex life and the very real handicap that is lymphedema. Dr. Hamel demonstrated an in-depth knowledge of the range of emotions of anyone dealing with

lymphedema: sadness, anger, mourning, fear, shame, helplessness, despair, all challenges that accompany patients throughout their lives. To better deal with these adverse effects, Dr. Hamel suggested two helpful tools.

The first is mindfulness meditation, which enables us to come to terms with physical, psychological and relational changes while savouring the present moment. This approach encourages us to let go of ruminations, dark thoughts, regrets and apprehension about what the future may hold. The second is **Acceptance and Commitment Therapy (ACT)**, which begins with setting objectives that make sense to us and which give meaning to our lives. We first identify goals and people who are important to us and whom we hold dear, in order to take positive, constructive action despite our lymphedema.

I will certainly have plenty to talk about when I next see my compression garment fitter!

Slowly, this exercise should lead us to acceptance of our new reality as well as acceptance of others and their wide-ranging attitudes and reactions. We start by asking if we are ready to embrace a new way of seeing ourselves, the world and indeed, life itself. Dr. Hamel highlighted a range of psychological services which could be offered to anyone living with lymphedema.

In closing, I thank the courageous patients, inspiring volunteers, motivated therapists and caring doctors whom I met at the conference. You have my utmost admiration for your commitment and the example you set. You are the people who will determine the future of lymphedema! **LP**



Anne-Marie Joncas is a patient who chose to put her communication expertise at the service of the Lymphedema Association of Quebec. As a copywriter-translator for 30 years, she writes, among others things, for health organizations. She also does contract translation work for the Canadian Lymphedema Framework and the National Lymphedema Network (USA).

Our interest is swelling

But what's in a name?

Interviewed (and prefaced) by Neil Piller:

BB Lee, Jane Rankin, Vaughan Keeley and Robyn Box

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We seem to have made strides in our ability to differentiate between lipoedemas and myxoedemas on the basis of clinical testing and presentation, but there is still a lot of uncertainty it seems when it comes to defining the boundaries between chronic oedema and lymphoedema.

We know that chronic oedemas are most commonly caused by elevated blood capillary pressures and we know the lymphatic system can fail to compensate for and remove the additional load. So when it does (or at least seems to) we use the term 'lymphoedema', or



for those more in the know, perhaps phlebo-lymphoedema. When the lymphatic system is malformed, damaged, or destroyed by cancer treatment, we call it lymphoedema.

We are also seeing an obesity epidemic in which one of the presentations is a limb swelling and associated fibrosis and papillomata, much like that of lymphoedema, but is it really lymphoedema?

There are differences between lymphoedema and chronic oedema, or so it seems. Many healthcare professionals may have problems defining and describing the differences in the late stages of them both without a barrage

of test and history taking. But how important are these names? How important is it for us to continue to use different names for what might, in many respects, be quite similar? Is lymphoedema a poor neglected sister of the larger chronic oedema brother? Is there some benefit of changing the names? Is there some danger of losing the uniqueness of each? Whatever we decide, it's clear we all need to work together (Piller, 2009; 2016; Partsch, 2014), but how is this best done and under what conditions?

We have invited some experts from around the world to debate some of these points and look forward to hearing what our readers of the *Journal of Lymphoedema* think as well.

Lymphoedema or chronic oedema—what are we looking at, can we and should we distinguish between them, what should be or could be different in terms of treatments, our expectation of outcomes, and what is essential and what is optional?

JR: Outcomes will differ, especially when we consider the impact of obesity and also lipoedema. However, our staff should be autonomous practitioners who, on assessment, will differentiate and plan the most appropriate management. This does

mean that we need to ensure that frontline specialists have the appropriate training and grade, and are the gatekeepers to all levels/types of service; this does not have to be medical as has been shown in several regional services. However, teams do need to have access to specialist medical teams for consultation when required. This includes access to investigations and genetic testing.

Differences in care, I suppose, relate most obviously to surgical options. The basic principles apply to all, but perhaps the lipoedema/obesity options will be what we need to clarify

to ensure efficient and effective care.

I think it is important to try and distinguish between different types of swelling, but not essential, and not at the expense of unnecessary medical tests.

Key treatment is compression, regardless of what type of swelling (and obviously if there are no contraindications to compression). I agree that obesity-related swelling should focus on weight loss and healthy lifestyle. The role of medication in oedemas of mixed aetiology is important to consider, although this is not our area of expertise.



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BL: They are as different as apple and orange! Like congenital vascular malformation (CVM) versus arteriovenous malformation (AVM) and venous malformation (VM). Lymphoedema is ONE of many different conditions belonging to chronic oedema. They all do have different management strategies, as well as prognosis/long-term outcomes (e.g. chronic venous stasis/ insufficiency; drug side effects). Hence, proper differential diagnosis to sort out various natures, as we currently do, should be the starting point for the assessment. There should be no doubt before reaching the conclusion of lymphoedema. Not only local, but also regional and systemic causes ought to be included.



Clinical outcomes are likely to be different depending upon the aetiology of the chronic oedema. For example, dependency oedema in immobile patients, who are unable to go to bed at night and therefore sleep in a chair, can be very difficult to control.

Furthermore, understanding the aetiology may help to define methods of preventing/ reducing the risk of developing oedema. For example, passive exercises could be employed to try to prevent oedema associated with immobility, which is probably largely due to calf muscle pump failure.

Which members of the healthcare team should be leads in the identification, differentiation, treatment strategies and processes? Can the lead be the same regardless of the origins of the swelling?

JR: Regarding care provision, I think we have examples of leads from across the multi-disciplinary team and specialities. Currently, it all comes down to funding sources — and also interest to provide a service — sadly. I do, however, see many practices that are funded under the term ‘lymphoedema’ now accepting, or being referred patients, with all origins of swelling. Education of funders is, therefore, key. I suppose the ideal model would be to have a medical doctor as lead for the more complex/ unclear cases, although our model in Northern Ireland and Wales works well in that we have access to medical input when required. Having access to national clinics, such as St Georges and Derby, is important for the rarer conditions— but would not need to be the model for local commissioning. As mentioned, many of the chronic oedemas progress and develop lymphatic issues, so it would be difficult to assign all oedemas to a particular category.

BL: A family physician or general practitioner should initiate the investigation as a gatekeeper and set the right direction with the help by the referral specialists. Depending on the final diagnosis (e.g. iliac vein thrombosis), further management would be carried out by specialists (e.g. vascular surgeon to intercept the thrombosed iliac vein with angioplasty and stenting versus bypass).

VK: The skill sets required to identify and differentiate types of chronic oedema depend on the aetiology concerned. For example, in breast cancer treatment-related lymphoedema the cause is usually clear (i.e. the effect of surgery and radiotherapy). Appropriate therapy can then be carried out. However, the healthcare professional also needs to be aware of the possibility of recurrence of breast cancer, which could worsen the lymphoedema and require anti- cancer treatment.

In other clinical situations, such as older people with multiple comorbidities, the aetiology may be more complex and a variety of factors may contribute to the cause of the swelling. It is helpful to understand these factors so that appropriate treatments can be initiated.

RB: There will be regional variation in the members of the healthcare team, both from historical perspectives but also from healthcare practice and roles in the local healthcare systems. Insight into professional strengths and limitations is required. Recognition of the need for a collaborative framework for the timely and efficient differential diagnosis leading to appropriate, evidence based and cost-effective management is essential. For example the onset of unilateral lower limb oedema or lymphoedema can be assessed by appropriately trained clinicians, but

differential diagnosis may or should require imaging to exclude other causes (eg May-Thurner syndrome) or more sinister causes (malignancy or vascular obstruction), or provide a conclusive diagnosis (lymphoscintigraphy). Collaboration in the clinical setting works well without the lead necessarily being a medical physician, provided that inter-disciplinary communication and collaboration exists. An appropriate qualified and experienced allied healthcare professionals lead can and does reduce healthcare costs.

Do we really need the two terms? What are the advantages and disadvantages?

JR: We are trying to get referrals into services as quickly as possible, so is lymphoedema

Key treatment is compression, regardless of what type of swelling (and obviously if there are no contraindications to compression).



VK: The term ‘chronic oedema’ was coined as an umbrella term to describe chronic swelling of all types of aetiology (Moffatt et al 2003) for the purposes of

an epidemiological study. The word ‘chronic’ was defined as being present for at least 3 months. It was important to standardise a definition so that prevalence data from different geographical areas could be compared.

‘Chronic oedema’, therefore, encompasses lymphoedema, venous oedema, immobility-related oedema, oedema of advanced cancer and oedema of mixed aetiology among others. In most clinical situations, the cause of the oedema is not purely a lymphatic problem. In the clinic, it is important to consider the different components causing the oedema to enable appropriate treatment. For example, in older people with chronic swelling, heart failure may be a contributor to the aetiology. Treating the heart failure is, therefore, an important part of the management of such swelling.

always chronic? Can't we manage it in latency stage? On the other hand, chronic lymphoedema may lose the fluid aspect of its pathology to fibrosis and adipose tissue. Is lipoedema actually chronic oedema in an early stage? It isn't lymphoedema, as least insofar as it has got a functioning lymphatic system in the first instance.

BL: Yes, we need two separate terms. We cannot lose the bird's eye view since many phleboedema with/without ulcer would proceed to combined condition of chronic venous insufficiency (CVI) and chronic lymphatic insufficiency (CLI) known as (secondary) phlebolymphoedema.

VK: On the basis of the "new" understanding of the mechanisms of interstitial fluid production and removal, where reabsorption of fluid from the interstitial space into the venous end of the capillary is no longer felt to occur in the steady state, the lymphatic has the major role in fluid removal. It could be argued that all chronic

oedema is lymphoedema, as failure of lymph flow to drain all the fluid filtered is a component of all oedema. In some situations, lymph flow is reduced from normal (e.g. lymphoedema) whereas in others (e.g. venous oedema) lymph flow is increased as capillary filtration is high, but the increased flow is inadequate to keep up with the high filtration rate so that oedema develops (high output failure). In the latter example, over time, the lymphatic becomes damaged and lymph flow reduces.

Nevertheless, the term chronic oedema has advantages because of its general nature. Not only is it valuable in creating comparability of prevalence studies, but it encourages the consideration of the aetiology of chronic swelling in individual patients and therefore the appropriate treatment.

However, internationally, when the term 'lymphoedema' is used, many people consider this to be the swelling that occurs after cancer treatment and other causes of chronic swelling are not included. A lot has been done to change this concept and,

In most clinical situations, the cause of the oedema is not purely a lymphatic problem. In the clinic, it is important to consider the different components causing the oedema to enable appropriate treatment.

therefore, a better understanding of the wider causes of lymphoedema (primary and secondary) is beginning to occur. The introduction of the term 'chronic oedema' therefore may cause confusion.

RB: Yes we DO need the two terms as they assist in distinguishing patient groups in the clinical setting, which also provides a variety of clinical algorithms for appropriate management.



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What is your preferred general treatment/management strategy when a patient with a long-standing oedema presents?

JR: My preferred management strategy depends on the cause of swelling. A patient with previously untreated primary lymphoedema with typical lymphoedema skin changes will be treated differently to a person who has long-standing oedema due to obesity. Core management strategies for all patients should include self-management, exercise and compression.

Self-management should be core to the treatment strategy. This must challenge the culture of “the therapist will fix me”! Partnership and accountability must be built into each management planning contract. This must have front-loaded education sessions as per all long-term condition models, such as the use of wrap round services, such as weight management classes and activity groups in locality. Also consider the family picture—is it genetic?

BL: Whenever there are predisposing factors for the condition to progress, despite maximum implication of conservative regimen (e.g. manual lymph drainage [MLD]-based, decongestive lymphoedema therapy [DLT] for lymphoedema), appropriate care should be considered to negate further progress or deterioration (e.g. lymphatic reconstruction including lymph nodes transplantation while in compensatory stage).

VK: My preferred treatment strategy depends upon the cause of the oedema. However, at present, for most cases of chronic oedema, DLT is an appropriate part of the management.

RB: Chronic oedema, which is differentiated from confirmed primary and secondary lymphoedema, is managed with education regarding causes and contributing factors to chronic oedema, skincare, appropriate elevation, sequential muscle pump exercises and compression therapy. If needed, a short course of compression bandaging to optimise prior to fitting compression garment can be

beneficial. If a wound is present, management of the wound with appropriate wound care and dressing is necessary. Low level laser therapy and compression may be helpful.

Primary and secondary lymphoedema management will depend on previous diagnosis and management, adherence and outcomes. Problem-solving with the individual is essential for people with long-standing lymphoedema to identify barriers to effective self-management and ongoing improvement.

Is there some benefit of changing the names of oedema and lymphoedema, or there some danger of losing the uniqueness of each and their associated health funding and recognition?

JR: As a manager who has worked long and hard for funding, it does seem to matter having different names as funders are beginning to know what lymphoedema is, but the term chronic oedema is still a bit too nebulous. Also many funders, such as Macmillan Cancer Care, will support clinics that focus on lymphoedema, but not on



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chronic oedema. It's a problem for the current thinking, and perhaps in the future this will change – but it has taken 20 years in the UK for the lymphoedema message to be heard!

BL: I see no reason to consider changing the name since the recognition of 'lymphoedema' as one of the major players in chronic limb swelling has increased in the last decade. Indeed, as the fruitful outcome of active campaign mostly by phlebologists (not by lymphologists), the lymphatic system/circulation has been recognised as an 'inseparable' dual drainage system with venous system.


VK: At present, the term 'lymphoedema' describes oedema due to failure of lymphatic drainage. This is usually used to describe a situation where the primary problem is failure of the lymphatic system. Other terms are sometimes used, such as phlebolymphoedema, to describe aetiology which is primarily due to failure of other systems, in this example the venous system.

The failure of the venous system leads to subsequent failure of the lymphatics hence the term phlebolymphoedema. In this situation, it could be argued that addressing the problem of the venous system failure may prevent subsequent failure of the lymphatics and worsening of the oedema. Therefore, by qualifying the term lymphoedema it is possible to draw attention to the underlying primary problem. So the term 'lymphoedema' could be used more widely with such qualifications. The term 'chronic oedema' more accurately covers the real world of oedema of mixed aetiology and, therefore, has some advantages.

Finally, it could be argued that the term 'lymphoedema' be used as a synonym for 'chronic oedema' to avoid introducing a new term but, at present, I think this could lead to further confusion.

RB: A considerable amount of time and effort has been spent by many people the world over to increase awareness of both lymphoedema and chronic oedema – this appears

The term 'chronic oedema' more accurately covers the real world of oedema of mixed aetiology and, therefore, has some advantages.

to have gained momentum, with changes in referrals and increased awareness by health-care professionals and public. Changing the names may create more confusion, but regional/national differences will impact on this in terms of funding. It is important to ensure that all appropriate healthcare providers are identified in the funding models. 

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Questions from the 2017 Canadian Lymphedema Conference

We were fortunate at the 2017 National Conference to have a panel consisting of experts from around the world.



Dr. David Keast is the Medical Director of the Chronic Wound Management Clinic at the Parkwood Institute in London, Canada;



Dr. Tobias Bertsch has been a senior consultant at the Foeldi Clinic in Hinterzarten, Germany since 2005, specializing in lymphology and bariatric medicine;



Dr. Alex Munnoch has been a consultant plastic surgeon at Ninewells Hospital, Dundee, Scotland for the past 13 years. He has been providing a surgical treatment option for lymphedema patients for 12 years, and has presented his results at numerous national and international conferences;



Dr. Nicole Paquette is a dermatologist, has practised in Pointe-aux-Trembles for 27 years. Her interest in lymphedema grew out of her daily practice where she sees a large number of patients referred for complications related to lymphedema;



Dr. Anna Towers, who moderated the panel, is an Associate Professor of Oncology, McGill University and Director of the Lymphedema Program, McGill University Health Centre (MUHC), since 1995.

The following questions were posed by conference delegates and have been transcribed and adapted for print.

Q What is the advantage of wearing compression garments at night?

Towers: If you live in a climate where summers are very hot, sometimes we say to patients: “if you don’t want to wear your garment during the day, get a night garment that is not so elastic” and there are many kinds—Velcro™, padded, or those that you put a bandage on top of for nighttime. For some patients, just wearing garments during the day is not enough. We try to get people under control to the point where they only need garments during the day, but some people, in order to control their edema, need 24 hour compression. I also wonder if after liposuction surgery for lymphedema, whether patients require 24 hour compression?

Munnoch: Yes, unfortunately standard protocol is 24/7 flat knit garments, for life. It’s perhaps less of an issue with legs at night, but sadly, with lymphedema in the arms—and you’ll notice this even if you sleep with a ring on, that in the morning the ring fits tight—because all that fluid that settled in your legs during the day is redistributed overnight throughout the rest of the body and you get some extra edema in the limb. If you’ve got lymphedema, keeping that compressed and keeping fluid from collecting in the first place is very important.

Towers: Some people need 24 hour compression. Also, after intensive therapy when you’re in 24 hour compression with

bandages, or whatever compression system you’re using to reduce the amount of swelling, there might be a transition period of several weeks or longer. As you get used to your new garment you might need night compression, or you might need to bandage at night during this so-called transition period. The final result, hopefully, is that you just have to wear the garment during the day.

The other time you might want to bandage at night and during the day is before you get measured for a new garment. So if you’re going to get a new garment every 4-6 months, some therapists suggest that for a week or so before getting measured, you use 24 hour compression so that when you get fitted for the new garment, you’re at your very best measurement. And of course, get measured in the morning if you can.

Q How do you frame the dietary or nutritional counseling done at your clinic to distinguish it from a “diet”?

Bertsch: Usually when you use the word diet, you think of a commercial diet, like Weight Watchers™ or a ketogenic diet. Diet from the Greek origin means “healthy life,” and I think when we use it in this sense, it makes dieting sound nicer, the word is actually quite often misused. One and a half years ago at the Foeldi clinic we eliminated sugar from patients’ diets completely, and reduced processed food. We expected a storm of complaints from the patients, but did not receive a single one. So, that’s one

way we use diet in the clinic. We also give nutritional advice and education to patients who are in the bariatric program, by teaching the patients about supplements and how they should be eating following their bariatric surgery. But we do not offer “diet” advice in the commercial sense.

Q If an obese person does succeed in losing weight, are the pathological hormonal changes that you described in your presentation, reversible?

Bertsch: Data shows that the change that occurs to the hormones remains for as long as seven years. Some people are successful, but seven years is a very long time, so, you have to be extremely disciplined long-term after losing weight to maintain this.

Q The delegates today have been very moved by the discussions on obesity and the rising obesity rate. What can we do? What can educators, physicians, researchers, the lymphedema professional community do in order to prevent lymphedema and its co-morbidities?

Bertsch: Great question. From my perspective, the most important thing a therapist can do when they have a severely obese patient in front of them is to talk to them about their obesity. I’ve noticed that for many, this is a very unpalatable topic, but you need to address it. I usually ask the patient for permission to talk to them about their weight issue after having addressed the other issues

they are seeing me for. I have never had a patient refuse when I approach it in this way. This is the first and most essential step. Don’t ignore it. Don’t be shy. The patient is usually grateful if you can speak about the topic in a way that doesn’t put the blame on the patient and is respectful. There are different problems that cause obesity. When you treat your patient, address all the different potential causes for the excess weight, from genetics, to pregnancy, to sugar consumption, even to depression or other stress related conditions.



From left-to-right, Dr. Nicole Paquette, Dr. Tobias Bertsch, Dr. Alex Munnoch and Dr. David Keast field questions.


Self-acceptance is a key point to bring up with them, as well. The movie, “Embrace” is a movie every lymphedema patient should see. In fact everyone should see this movie. It will change your outlook of your body shape.

Q Are there any pro bono services available for lymphedema?

Towers: I see this more as someone crying out than as a question. Reading this question expresses what we see in

our clinics on a daily basis. We have very desperate patients who are looking for treatment, so I just want to put this question out there for comment from our panel.

Munnoch: We understand your cry for help, indeed. In the UK, we have National Health Service but many services, such as lymphedema surgery within that is not recognized. I’ve seen a patient refused funding for surgery who had two litres of excess fluid in her arm after breast cancer surgery because A) liposuction is considered a cosmetic procedure, and B) because the patient was fully informed and consented to an axillary lymph node biopsy, which included the risk of developing lymphedema. Because she’d issued consent to a surgery that could potentially cause lymphedema, they would not fund the treatment of that lymphedema. In different healthcare systems worldwide, you’ve got different issues appearing.

Paquette: I think what is important is the strength of numbers. The prevalence numbers we saw this morning demonstrate that this is a significant problem. I think government ministers need to be informed of this. For example, the Lymphedema Association of Quebec was able to convince the Government of Quebec to pay for a percentage of compression garments. I think we all need to be members of our provincial associations, we should foster visits with politicians. It’s the strength of the numbers that will convince them that this is a significant problem. It’s important to shout out loud and broadcast the significance of this problem. 



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Exercise: Lymphedema's best friend and worst enemy

Taking control of your lymphedema means not giving up

An inspiring dedication to exercise, despite many bumps in the road

By Kathy Woudzia

I am a 54-year-old woman who developed lymphedema at the age of 25 while pregnant with my third child. I can vaguely remember a time when I enjoyed wearing shorts or dresses. I barely remember what it felt like to wear my bikini and hang out with friends on the beach like a "normal person." Instead, I need to arrive armed with a lawn chair to elevate my leg, loose beachy pants and psychedelic tights to wear over my compression garment for water sports. I bring alcohol wipes, bandages, antibiotic cream, and antibiotics to evade any infections. So much for feeling good in a swimsuit and not drawing attention to myself!

At a certain point, I realized I needed to figure out how to make my health and mental state the best they could be. Lymphedema has certainly defined me in many ways, but there is one thing I won't allow it to take control of—my wide variety of fitness endeavors.

I have never considered myself an athlete. As a child, I was average at all sports and fitness activities. Having said that, I've always been very athletic and believe exercising and fitness are absolutely wonderful. As a teenager, I was actively involved in ice-skating, water-skiing, basketball, field hockey, snow skiing, and running. I ran throughout my pregnancies. I later purchased exercise tapes, and the children became my audience as I bounced around in my leotard, tights, and leg warmers.

My first interruption to fitness took place when I was pregnant with my third child. A large purple patch developed on my left leg, just above my knee, and my entire leg began swelling. I was rushed to the hospital, six months pregnant, with a "mysterious" infection. Then three weeks before the



baby was due, I got sick again and was hospitalized for three weeks. I remained there to give birth to my beautiful daughter on December 31st. Post-pregnancy I was happy to see that the swelling in my left leg went down and the leg was close to, though not quite back, to its original size. Years later I

"Exercise made me feel like lymphedema wasn't controlling my life. Rather, to a certain extent, I was controlling it."

learned these "mysterious" illnesses were really bouts of cellulitis and the beginning signs of lymphedema.

For the next three years or so I didn't really give it a second thought. Life was busy with three children, two jobs, work on a university degree and daily exercise. Yet my sanity was always just a fitness workout away. Then one day, out of the blue, my life turned upside down. I suddenly developed redness on my leg, a fever, and my body felt achy. There wasn't a physician around that could identify the nature of the illness. Five days later and practically on my deathbed, a dermatologist finally diagnosed and subsequently treated me for a streptococcus cellulitis infection. I suffered from 10 subsequent bouts, all within a 15-month period. I should have listened to my friends, doctors and family members when they insisted I take some time away from my hectic schedule, but I felt pressured to keep up with all of the work at the expense of my health. The build-up of scar tissue in my left leg effectively blocked all of the deep tissue lymphatics. What did I learn? Listen to your body!

My brain was plagued with questions like, "How is this chronic condition going to change my life", and answers like, "Every



Kathy Woudzia is the mother of 5 children between the ages of 15 and 33, the grandmother and daycare provider for a two year old granddaughter, and married to an amazing, caring husband. She has a background in Kinesiology, and Library Science. Kathy has been living with primary lymphedema of her left leg for almost thirty years.

possible aspect of it?" I was going crazy obsessing over the fact that I had a condition that was irreversible and, about which neither my doctors nor I knew anything. In addition, I was living in a small rural town without any support. Having lymphedema was very difficult for me, both emotionally and physically. However, I decided this illness wasn't going to stop me from doing the sports I loved. Within the next several years I ran a marathon, completed a duathlon in record time, ran in a variety of 10K races, cycled 100 km, and hiked many mountains.

In 1999, I married my wonderful new husband and moved to Vancouver, BC. I continued running and cycling and began weight training. My husband and I really wanted to expand our family. Despite concerns that a pregnancy could potentially aggravate my lymphedema, we decided to have a child. Throughout my pregnancy, I continued to work out with light aerobics and weights, but my leg still swelled more than usual. Once I gave birth to our amazing daughter, the swelling in my leg decreased slightly. My therapist, Catherine DeCecca,



provided MLD sessions twice a day for 10 days. I began working out lightly again, listening closely to my body with regard to intensity and duration. My leg continued to decrease in size and I was fitted for smaller support garments fairly frequently.

Two years later, I had another setback. Because of a fitting problem with my compression garment, I developed an infection in my Achilles tendon, which lasted an entire year and was excruciatingly painful. I was prescribed pain killers and was not able to continue my routine workouts. Mentally, that was very difficult for me. It also proved to be a problem for my leg because there wasn't as much lymphatic flow taking place due of lack of movement. The wound finally healed only because a specialist garment fitter from Austria made a remarkably simple, but

"Lymphedema has certainly defined me in many ways, but there is one thing I won't allow it to take control of—my wide variety of fitness endeavors. I have never considered myself an athlete."

effective decision to increase the ankle measurement of my compression garment. I was elated. I stopped my pain medication and was able to resume exercising. My life went from darkness to light again.

I started exercising again by spinning and practicing indoor aerobics and went on to pursue many activities such as hiking, biking, stair climbing, boxing, running, walking, hiking, surfing, climbing and strength training. To avoid injuries due to overuse, I believe variety is essential when exercising for anybody with or without lymphedema.

Doctors and massage therapists are pleasantly surprised when they notice very little difference between the size of my two legs and find the skin is very healthy looking. Both agree that this is due to a lifetime dedication to physical fitness.

I've always worked out to keep my sanity, but without knowing it at the time, I was continually building muscle and thereby improving my leg lymphedema. Exercise also relieved my stress, which in turn helped reduce cortisol levels in my body. Studies have shown that increased cortisol levels cause inflammation and anything we can do to reduce stress positively affects many conditions including lymphedema. Lymphedema has a psychological impact as well as physical. Exercise helps to keep my body at a healthy weight, but also makes me feel better—both in the short term (release of endorphins) and in the long term (positive body image). The positive mental state, and increased lymph movement in my leg, are pleasant by-products of working out. What a nice surprise! **LP**

My personal revelations:

- When I don't work out or I am inactive during the day, my leg feels fuller.
- If I overwork my body, my leg also takes a hit: the key is the balance between exercise and rest.
- Standing, or sitting with legs down, are the two worst positions for lymphedema of the leg.
- When you move and work your muscles, the muscle pumps act on the lymphatic vessels helping them move fluid through and out of the body.

Adapted Nordic Walking: A comprehensive and universal exercise program

Recommended for those diagnosed with lymphedema

By Chantal Turgeon

History

Historically, shepherds and pilgrims have used walking sticks to assist their mobility. As time progressed, using walking sticks modernized as well. In the 1950s, cross-country skiers trained during the summer months by walking while pushing on poles to simulate sliding. The first scientific studies on the positive impacts that Nordic walking has on health began in Finland in the 1990s. The Nordic walking we know today was conceived in 1996, thanks to a collaboration between Finnish sports experts and a sporting goods manufacturer. Together, they created poles specifically for Nordic walking. In 2002, Finland was home to over one million Nordic walkers out of a total population of 5 million! Today, Nordic walking has participants in over 40 countries and has been established as one of the most popular sporting disciplines in Europe.



Anne-Marie Joncas of the Lymphedema Association of Quebec.

Equipment

Poles equipped with special grips are an essential component required in order to master the skill of Nordic walking.

Specialized poles are made of aluminum, or ideally of a mix of carbon and fibreglass. This blend of materials helps to avoid vibrations in the elbows and in the arms during each forward motion thrust, and also ensures that the poles are lightweight. This helps the Nordic walker avoid developing pain in the elbows and/or shoulders.

The grips are outfitted with straps that have a hole designed for the thumb to pass through, resembling a gauntlet. These are attached to the handle of the



pole, and allow the walker to release and automatically catch the pole to initiate the key fluid and rhythmic movements that characterize Nordic walking.

The technique

Since Nordic walking mimics the natural biomechanical movements of walking, it is generally quite easy to learn.

The thrust initiates rotation in the torso:

The poles contribute to exaggerating the natural movement of the arms and help to propel the body forward. When properly executed, this dynamic thrust activates major muscle groups, using 90% of the muscles in the body, all without putting stress on the joints.

The inclusion of the hands: The cadenced altering of opening and closing the hands



Chantal Turgeon MT, CDT, ALT, is a certified lymphedema therapist of Dr. Vodder School-International in 2007. She currently works at the kinesiology clinic of the Breast Cancer Clinic of the Royal Victoria hospital in Montreal. She has been a certified Nordic Walking Instructor of the International Nordic Walking Association (INWA) method in France since 2012.

creates a pumping action that stimulates the circulation of blood and lymphatic fluid.

The foot roll: Mastering the technique for Nordic walking requires learning the foot roll, and using it to propel the stride, exercising muscles and joints that aren't often engaged.

The benefits

It has been reported that Nordic walking has a significant and positive impact on posture and balance¹, and that it improves upper-body strength².

Nordic walking is an exercise that can help to control and treat lymphedema because:

- Without seeming like an intense level of effort, Nordic walking raises the heart rate and as a result, activates lymphatic circulation.
- It requires significant participation from the bicep, tricep and anterior deltoid muscles which are often deconditioned following breast-cancer treatments
- The rotation of the torso that is induced by the thrusting action engages the postural muscles and improves the effectiveness of the diaphragm. This improves breathing and consequently creates a better pumping of the lymphatic system³.
- At a moderate pace, completing a Nordic walking workout burns up to 40% more calories than traditional walking. This creates an advantage when it comes to weight control, which is an essential component of lymphedema management.



Adapted Nordic walking

Following international recommendations for a slow and progressive re-integration of physical activity⁴, “adapted Nordic walking” combines the core techniques of Nordic walking with exercise intervals that are



recognized as being beneficial to lymphedema management. For example, Casley-Smith exercises⁵, the Isa method⁶, diaphragmatic breathing, self-massage, exercises derived from the Vodder method and

Tai-Chi movements can be integrated into a Nordic walking workout.

Exercise is recommended for patients who ideally have their lymphedema under control. However, the intensity of the exercise regimen can be adapted to different needs and should allow for gradual rehabilitation without over-exertion for those newly diagnosed with lymphedema. Since the poles help to add balance and stability to the exercise, Nordic walking can also be adapted for those who are facing side effects related to chemotherapy, such as neuropathy or loss of balance.

Nordic walking course structure


Courses are based on learning the ten steps specific to Nordic walking. For each course, participants start with warm-up exercises, then move into the core Nordic walking phase, which is intercut with intervals of exercises adapted for lymphedema, and finish with stretches.

In conclusion

Nordic walking is a physical activity that is accessible to all⁷. This total body workout is easy to learn, safe and cost effective. Nordic walking is based on movements that complement the body's natural biomechanics and it entails very little risk, since the poles ensure excellent stability. In addition, this activity is easily adapted for a variety of

different physical or medical conditions.

A recent systematic analysis of scientific literature concluded that in addition to recognizing that physical activity has an impact on the reduction of rates of cancer relapse, a slow and progressive return to exercise is safe and beneficial for those diagnosed with lymphedema⁸. It has been shown⁹ that long-term, weekly practice of Nordic walking will have a noticeable impact on lymphedema control and on overall fitness levels. The INWA (International Nordic Walking Association), which is based in Finland, declares that “regularly practicing Nordic walking will have a positive impact on overall quality of life: it will lead to a significant improvement in physical fitness, and social, intellectual and psychological condition, all without an environmental impact.”

For these reasons, Nordic walking should appeal to cancer survivors who are aiming for optimal management of lymphedema and have a goal of an improved state of wellness in every facet of their lives. 



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

Hints and Tips

Sports shirts

Medical compression shirts for truncal lymphedema can be very expensive. Sportswear like the Nike Pro shirt work well for some people and are more affordable. You might consider buying a few sizes smaller to add the compression element. Also the V-neck allows it to go almost unseen when worn... and it comes in a bunch of colors. Adapted from Lymphwars.blogspot.co.uk

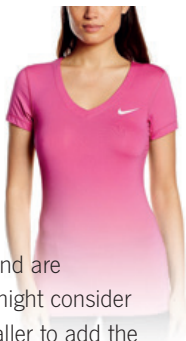


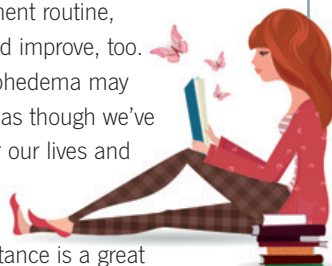
Photo: Nike

a cheerful color, or wearing soft, comfy socks. Lymphedema maintenance routines can become an extension of “me-time”: when using a compression pump or doing manual lymphatic drainage, use it as time to read a few chapters of a book or catch up on the latest episode of your favourite TV show.

It may seem silly but doing these things really helps re-frame the way you might think about your lymphedema and your body — it’s like a little peace offering

to yourself! Without the resentment you might be much more compliant with your treatment routine, so swelling could improve, too. Living with lymphedema may sometimes feel as though we’ve lost control over our lives and our bodies, but exercising self-care and acceptance is a great way to regain it. www.thelymphielife.com

Adapted from www.thelymphielife.com



Pampering yourself

Take time to pamper your lymphedema leg by doing things like rubbing moisturizing lotion on your legs, painting your toes

Send us your hints and tips

Why not make it easier for those living with lymphedema by sharing your practical day-to-day living tips with us? We invite patients, caregivers and health professionals to send in your suggestions and photos to pathways@canadalymph.ca.



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Did you know?



Hollywood support grows

Actor Stephen Guttenberg joins the fight for raising awareness for lymphedema. "My mom has lymphedema and so, like all affected families, I feel that I have lymphedema," Guttenberg said in a press release. "And that's why I support LE&RN in creating the awareness that will lead to a cure. LE&RN's President & CEO William Repicci noted that diseases like Lymphedema and lipedema begin to come out of the closet when people like Guttenberg use their celebrity status to raise awareness. Source: Lymphatic Education and Research Network

Photo: TV Guide



resources for lymphedema are above the recommended levels for readability and complexity with the suitability barely adequate for the intended audience. Overall, these materials are too sophisticated for the average American adult, whose literacy skills are well documented. Further efforts to revise these materials are needed to improve patient comprehension and understanding.

Source: J Surg Res. 2017 June

Editors Note: The Canadian Lymphedema Framework aims to provide appropriate level information on its website and welcomes feedback from *Pathways* readers and website visitors on improvements that can be made.

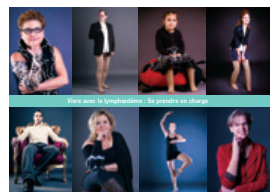
www.canadalymph.ca

Keep it simple

Researchers in the USA reviewed the top 10 highest ranked lymphedema websites (as per the Google search engine). Website content was analyzed beyond just the reading level of patient-oriented materials and included analysis on complexity, density of data as well as text design, vocabulary and organization. The results showed that the overall suitability score was only 45% correlating to the lowest level of "adequate" suitability. They concluded that online

French patient booklet

The CLF publication entitled "*Lymphedema: Learning to take charge*" is now available in French. The updated version of the booklet includes 4 extra pages emphasizing compression therapy and self-care. Contact the Lymphedema Association of Quebec for copies. www.infolympo.ca




Nova Scotia welcomed

The Canadian lymphedema community welcomes its newest provincial lymphedema association. Lymphedema Association of Nova Scotia was incorporated in October 2017, by founder Karen Bingham. Karen lives with primary lymphedema and is eager to join the provincial efforts to raise awareness and advocate for lymphedema care reimbursement in her province.

www.lymphedemanovascotia.com



Pathways survey results

The Canadian Lymphedema Framework has published 24 issues in the last 5 years of *Pathways*. Readers from across Canada, the United States, Europe and Australia enjoy the magazine. We thank all those who completed the Readers survey. A full report of the results of the survey will be shared in the Spring issue of *Pathways*. Feedback will be used to improve the magazine, by emphasizing the type of content favoured by our readers and integrating suggestions made. 

Book Review by Dr. Anna Towers

An Expert's Review of "Let's Talk Lymphoedema"

Book authors: Professor Peter Mortimer & Gemma Levine

I was pleased to see this excellent new resource book that will be valuable to both patients and therapists. The fact that the book is co-authored by a world expert as well as a lymphedema patient makes it a superior resource for advice and support. It includes quotes from many sources: professional advice and patient experiences of dealing with lymphedema. Although British-based, it does include views from around the world.

Professor Peter Mortimer, a dermatologist, has spent most of his professional life in lymphedema practice and research. I would recommend this book to any patient. The patient stories render this book a little portable support group! Although this book is written primarily for patients, given that it is written by an internationally recognized expert it is also authoritative. It is also good for health professionals to read this to understand the kinds of information that is most valuable to patients and also what kind of information would give them comfort. It would make a good reference for lymphedema therapists who would like to know what to include in educational sessions for patients. It is written clearly and is easy to understand. Order online at www.canadalymph.ca



Canadian and International Events

April 10 – 26, 2018
Montreal, Quebec

Complex Lymphatic Therapy: The Casley-Smith Method.

The Lymphedema Association of Québec in collaboration with McGill University Health Centre (MUHC) Lymphedema Program are pleased to present an intensive 144-hour clinical certification course in lymphedema treatment. Instructor: Bonnie Lasinski MA, PT, CLT-LANA. ■ www.infolympo.ca

May 17-19, 2018
Brisbane, Australia

Registration is now open for the **12th Australasian Lymphology Association Conference**. "Stronger Together", the conference theme, highlights the opportunities for success when people work together to solve the big unanswered questions that lymphoedema brings.

■ www.ala-conference.com.au

June 6-9, 2018
Rotterdam,
The Netherlands

8th International Lymphoedema Framework Conference.

This event will be co-hosted by the Dutch Lymphoedema Framework. The venue is the legendary former steamship SS Rotterdam. All sessions, guest accommodation and entertainment will take place on this ship. The hosts look forward to welcoming you onboard. Registration is now open and the abstract submission deadline is January 31, 2018.

■ www.2018ilfconference.org

2018 Dates
Canada and
the United States

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.



Letters
to the **Editor...**

Dear Anna. It was nice to meet you this morning by phone. As mentioned, I had a chance to view for the first time your *Pathways* publication. It's very impressive. Thank you in advance for looking into 50 extra copies of the Fall 2017 issue that we would like to purchase.

David Cory
President and
CEO, Eiger BioPharmaceuticals
Palo Alto, California

I attended your presentation on the Canadian Lymphoedema Framework and *Pathways* at the ALA/ILF conference in Darwin in 2016. I am a lymphoedema therapist in Australia and interested in subscribing to your wonderful *Pathways* magazine.

Leonie Naumann
President Australasian
Lymphology Association

We would love to hear from you...

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

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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.

The CLF distributes *Pathways* including customized inserts through its provincial partners.

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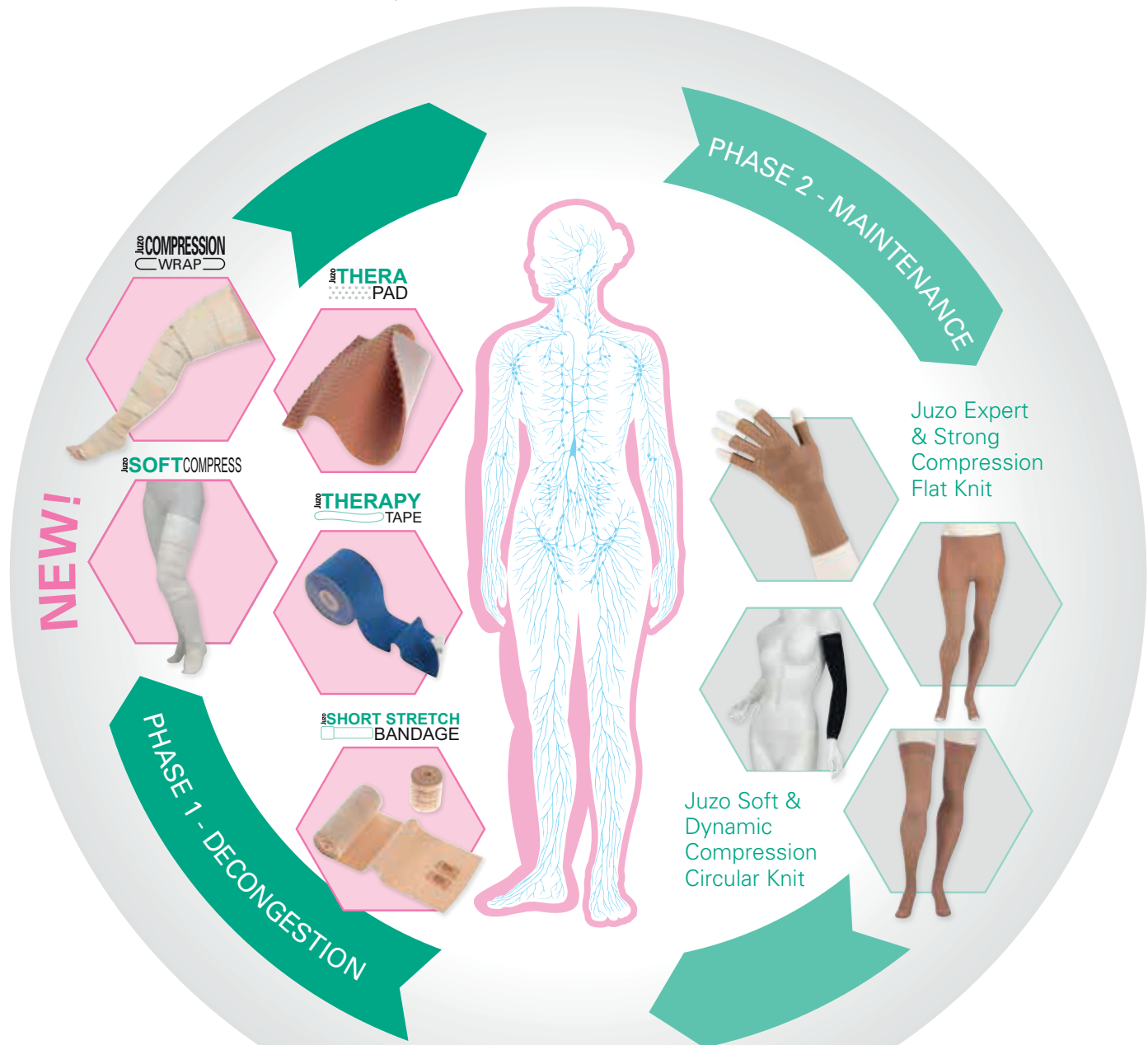
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