

A large, artistic watercolor illustration of a butterfly in shades of blue and teal, set against a dark background with splatters and other faint butterfly outlines. The butterfly is the central focus, with its wings spread, showing intricate patterns and colors. The background is dark with various shades of blue, green, and black, featuring splatters, dots, and faint outlines of other butterflies, creating a layered and artistic effect.

# Lymphedema

Association of Ontario

**2023 Resource Guide & Professional Directory**



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# Our Mission

We are committed to improving the lives of people living with lymphedema.

## Our History

In 1996 a group of lymphedema patients and family members, responded to the absence of support services for those suffering from Lymphedema by founding the Lymphovenous Association of Ontario.

Later the name Lymphedema Association of Ontario ("LAO") was adopted thereby allowing the LAO to more actively promote lymphedema education, prevention, treatment and quality of life for those with the condition.

Over the last 27 years the scope of the LAO has expanded with a view to realizing the ideals and mission of our Founders which remain our first and foremost priority ~ supporting the needs of individuals living with Lymphedema.

The work of the LAO would not be possible without the work our dedicated volunteers, valued members, generous donors and Board of Directors.






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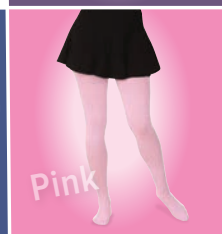
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# 6 Things patients Should Know About Lymphedema

## 1) What causes lymphedema?

Lymphedema is a chronic inflammatory condition and is characterized by chronic swelling that can occur in any area of the body

- Head/Neck
- Genitals
- Chest wall/breast
- Limbs

## 3) What are the potential complications of lymphedema?

Some complications of lymphedema include:

- Reduced mobility
- Cellulitis
- Chronic pain
- Psycho-social impacts
- Limited ADLs

## 5) What are the signs and symptoms of lymphedema?

Some of the signs and symptoms of lymphedema include:

- Heaviness
- Aching
- Swelling

## 2) What is lymphedema?

Any condition that overwhelms the lymphatic system

### PRIMARY

- Hereditary
- Congenital

### SECONDARY

- Obesity
- Venous disease
- Many cancers and their treatments (*lymph node dissection, radiation*)
- Surgical intervention
- Trauma
- Immobility
- Infection

## 4) Can lymphedema be treated by medication?

No medications exist to treat the lymphatic system

- Antibiotics and antifungals are used to treat cellulitis infections

## 6) What is the gold standard for treating lymphedema?

There is no cure for lymphedema but treatment exists called Complete Decongestive therapy, including:

- Manual lymphatic drainage
- Skin care
- Exercise and healthy eating
- Compression therapy

## Prevalence of Lymphedema for Canadians

	Canada 1 million for 36 million population*	Ontario 388,920 for 4 million population**
Chronic Venous Insufficiency: Undetermined		
Morbid obesity related	57%	
Cancer related		
Disabilities/Chair Bound	31%	
Surgeries (non-cancer)	8%	
Primary lymphedema	4%	
	2%	
	570,000	221,684
	310,000	120,565
	83,000	31,114
	40,000	15,557
	20,000	7,778

\*Mean incidence of cancer related lymphedema from systemic reviews

- All cancers: 15%
- Breast cancer: 18%
- Melanoma: 18% lower extremity 3% upper extremity
- Head and neck: 4%
- Gynecological: 20% uterine, cervical, vulva
- Genitourinary: 10% prostate, bladder, penile
- Sarcoma: 30%

Reference: Shaitelman et al 2015

\*USA up to 10 million LE (Stanford) extrapolated to Canada = 1 million. Canadian Lymphedema Framework 2018 \*\*National Census 2016. All numbers shown are approximate. This information does not replace the knowledge, expertise, skill and judgement of health care providers. It is not meant to be used for diagnosis or treatment.

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# Lymphedema Information

Lymphedema is chronic swelling of a body part caused by an accumulation of lymph fluid. If you have had cancer treatment, surgery, trauma or a genetic deficiency that has affected your lymph nodes, you are at a lifetime risk.

## The Lymphatic System

Lymph is a colourless fluid which forms in the body and normally drains back into the blood circulation through a network of lymph vessels and lymph nodes. The lymphatic system plays an important part in the body's defense against infection.

## How Lymphedema Occurs

If the drainage routes through the lymphatic system become blocked or damaged, lymph accumulates in the tissues and swelling occurs. Unlike other edemas, lymphedema leads to changes in the tissues, such as fibrosis and an increased risk of infection. The swelling can then become even more difficult to control. Types of Lymphedema Primary lymphedema develops as a result of a malfunctioning lymphatic system, usually as a result of genetic underdevelopment. Secondary lymphedema is the result of damage to lymphatic pathways. This may be a result of treatment for cancer following surgery or radiation therapy. Lymphedema can also occur as a result of infection, severe injury, burns, or any other trauma or surgery that causes damage to the lymphatic nodes and vessels. Lymphedema affects all ages and may occur months/ years after surgery, so it is important to understand and manage the life-long risk.

## Lymphedema Symptoms

The signs and symptoms for lymphedema may include:

- A full or heavy feeling in the affected limb
- A feeling of tightness in the skin
- Less movement or flexibility in the hand, wrist, shoulder or ankle
- Clothing or jewelry feels tight in one specific area
- Abnormal swelling in the affected area

Unfortunately, some people are told that nothing can be done to help. Many doctors are either not knowledgeable or are unaware of where to refer their patients for advice. Although there is no cure, there is help to manage this life-long condition.

**Lymphedema Management:** The goal of lymphedema treatment is to help reduce and control swelling, prevent it from getting worse and decrease the chance of complications. Ongoing self-care is crucial. The standard treatment is called Complete Decongestive Therapy (CDT).

The individual elements, used in combination, are: **Manual Lymph Drainage (MLD):** a specialized massage to redirect lymph fluid. **Compression Therapy:** elastic bandaging, compression sleeves, gauntlets or tights. **Exercise:** to promote lymphatic flow by activating muscle and joint pumps. **Excellent Skin Care:** the use of antibacterial cleansers and pH neutral lotions. The treatments must be performed by an experienced and certified therapist who has completed

at least 135 hours of post graduate training specific to lymphedema. We can help you find a certified therapist near you. Early diagnosis and treatment are vital to control lymphedema.

**Precautions & Recommendations Infections**

With damaged or blocked lymph drainage, you are at risk of infection (particularly cellulitis) in the affected area. Good skin care reduces the risk of infection.

If you feel generally unwell or have any sign of infection (fever, nausea, vomiting or a hot, red, tender, swollen limb) do not delay in seeking medical attention immediately. In most circumstances you will require antibiotics.

**AVOID**

- ✗ Cuts
- ✗ Scratches
- ✗ Burns
- ✗ Razors
- ✗ Insect bites
- ✗ Fungal infection
- ✗ Sunburn

**USE**

- ✔ Rubber gloves
- ✔ Gardening gloves
- ✔ Oven gloves
- ✔ Electric shaver
- ✔ Insect repellents
- ✔ Hygiene/skin care
- ✔ Strong sunscreen

**Trauma**

Any trauma or injury to the affected limb will increase your risk of infection and further swelling. AVOID whenever possible: injections, acupuncture, blood sampling and blood pressure readings from the affected limb AND tight or constricting clothing or jewelry PLUS extremes of heat or cold.



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## General Recommendations

- It is important to keep your weight within normal limits as much as possible.
- Try to use the swollen limb normally, as muscular activity encourages lymph drainage, but avoid sudden overexertion, as that may increase swelling.
- If your arm is swollen, avoid lifting or carrying heavy objects. If your leg is swollen, avoid standing or sitting with your legs down for long periods.
- Wear a compression garment when flying to help reduce any increase in swelling.

## What are the stages of lymphedema?



This is the difficult-to-see (subclinical) stage and the earliest presentation of lymphedema. There is no measurable swelling. Symptoms often reported include heaviness, aching and pins and needles. You can be in this stage for months or years before swelling develops.

0

1

Your swelling is detectable and measurable. The swelling subsides with the elevation of your affected limb. The swelling tends to come and go. There may also be pitting edema at this stage.

2

Early stage 2: Elevating your limb is ineffective and rarely helps to reduce swelling. Pitting edema will more typically occur at this stage.

2

Late stage 2: Tissue fibrosis is more evident in this period. Pitting edema may or may not occur.

3

Skin changes, such as thickening, darker skin (hyperpigmentation), skin folds, fat deposits and warty overgrowths, start to develop. Small pores in the skin can develop, and clear lymphatic fluid can leak out. The limb is hard and fibrotic, and there is no pitting at this stage.

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Reference taken from "The Complete Lymphedema Management and Nutrition Guide." Authors: Jean Lamantia, RD and Ann DiMenna,

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#### DRINK WATER

- 2-3 litres per day

#### LIMIT SALT

- 2300 mg/day



#### INCLUDE PROTEIN

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#### LIMIT FAT

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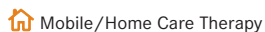
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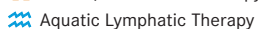
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bethhoagphysio@gmail.com  


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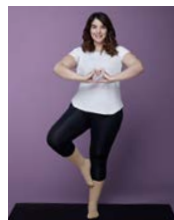
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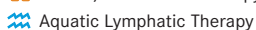


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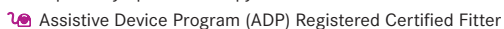
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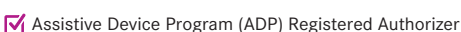
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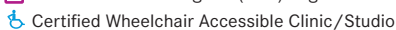
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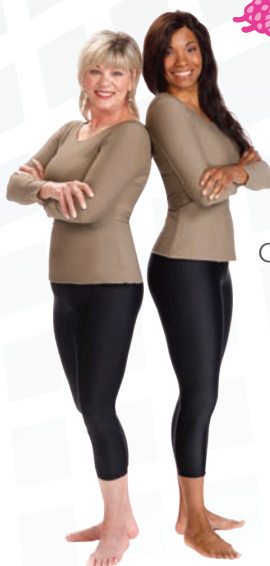
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All therapists listed have provided proof of their CDT certification from a LANA approved school where they received a minimum of 135 hours of post graduate training in lymphedema. **Disclaimer:** Therapists pay to be members of the LAO which includes a listing of their services. The LAO is not responsible for the services performed or rates charged.



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**Financial Assistance:** Professional members: The LAO offers a bursary program that you may nominate your patients for financial assistance

## Our Provincial Partners

- Alberta Lymphedema Association: [albertalymphedema.com](http://albertalymphedema.com)
- Lymphedema Association of New Brunswick: [lymphedemanb.ca](http://lymphedemanb.ca)
- BC Lymphedema Association: [bclymph.org](http://bclymph.org)
- Lymphedema Association of Manitoba: [lymphmanitoba.ca](http://lymphmanitoba.ca)
- Lymphedema Association of Newfoundland and Labrador: [lymphnl.com](http://lymphnl.com)
- Lymphedema Association of Nova Scotia: [lymphedemanovascotia.com](http://lymphedemanovascotia.com)
- Lymphedema Association of Quebec: <https://en.infolymphe.ca>
- Lymphedema Association of Saskatchewan: [sasklymph.ca](http://sasklymph.ca)

**Hospital Based Services:** <https://www.lymphontario.ca/Hospital-Based-Clinics>

**Support Groups:** [Lymphontario.ca/Support-Groups](https://www.lymphontario.ca/Support-Groups)

We are pleased to announce that we have launched our own monthly virtual lymphedema support group, created for and by people with lymphedema. We come together to share information, resources, hopes, fears, successes, and hardships in a safe space to co-create support and growth.

**Therapist Certification:** Certified lymphedema therapists are health professionals (nurses or doctors) or allied health professionals (physiotherapists, occupational therapists or registered massage therapists) who have gained additional post-graduate certification to specialize in lymphedema care.

Certified Lymphedema Therapy Training includes:

- Pathophysiology of lymphatic function and disorders.
- Manual techniques and compression bandaging/garment principles.
- Theory and practice of Complete Decongestive Therapy.
- Minimum 135 hours of post-graduate training (1/3 theory to 2/3 practical).
- Professional Standards of Lymphedema Training
- The Lymphology Association of North America (LANA) promotes standards for the management of lymphedema and/or related disorders. LANA advocates for the establishment and maintenance of certification for medical professionals who provide such services.

## Training Programs - North America

- Academy of Lymphatic Studies
- Klose Training & Consulting
- Dr. Vodder School International
- Norton School of Lymphatic Therapy
- International Lymphedema & Wound Institute (ILWTI)

## Assistive Devices Program (ADP) - ADP Information

[ontario.ca/page/assistive-devices-program](http://ontario.ca/page/assistive-devices-program)

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For forms go to: [Lymphontario.ca/Finance-and-Insurance](http://Lymphontario.ca/Finance-and-Insurance)

### **ADP Registered Authorizers, Fitters, Vendors**

Many of the LE MLD/CDT-Certified Therapists listed on our website are ADP Registered Authorizers. For more information about ADP Registered Authorizers near you email the ADP directly at [adp@ontario.ca](mailto:adp@ontario.ca). [www.ontario.ca/page/garments-pumps-and-braces](http://www.ontario.ca/page/garments-pumps-and-braces).



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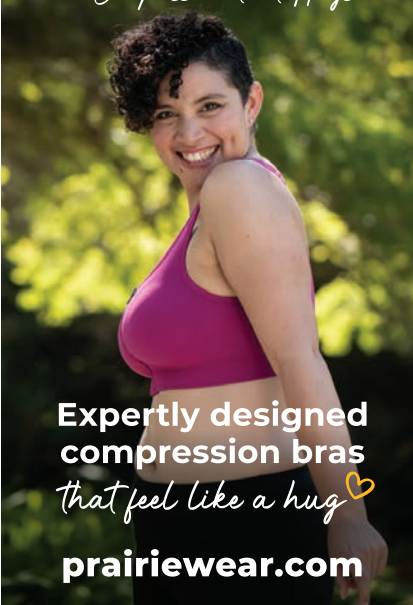
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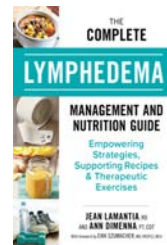
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## OUTREACH

Through our website, newsletter, educational events geared to patients, those at risk and health care professionals.

## ADVOCACY

For improved access to treatment and increased health care and insurance coverage.

## COLLABORATION

By strengthening partnerships with all stakeholders, promoting research and contributing to a stronger lymphedema community.

*\*We do not provide medical advice or treatment.*

## COMPASSION FUND

The mission of the Compassion Fund is to provide financial assistance for lymphedema patients who cannot afford the necessary treatments, with the goal of giving these patients the opportunity to work with a professional practitioner to assess their condition and learn how to manage and care for their lymphedema themselves.

## GARMENT FUND

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