

World Lymphedema Day Advocacy Kit



Support

We provide information, resources and help



Advocacy

For improvements to treatment and increased health care



Outreach

Through our website, newsletter and educational events

World Lymphedema Day

March 6, 2021 marks the 6th Annual World Lymphedema Day

World Lymphedema Day began in the US in 2016 and has since spread around the globe. Saturday, March 6, 2021 is the sixth annual World Lymphedema Day. The goal of World Lymphedema Day is to make cures for lymphedema and lymphatic diseases a global priority. It is estimated one million Canadians live with the condition.

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WHAT WE OFFER

A directory of qualified Lymphedema Therapists in Ontario

2

WHAT WE OFFER

A help line for anyone with Lymphedema concerns to contact us

3

WHAT WE OFFER

Information and resources for patients and their loved ones

Lymphedema Association of Ontario

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

We have been doing this since 1996. Our founders, a group of lymphedema patients and their families responded to the absence of support services by setting up the Association. We have always kept the needs of people living with lymphedema front and centre. Our work continues to be made possible by our volunteers, donors and members.

We actively promote lymphedema education, self care, prevention, treatment and quality of life for those living with the condition.

In Ontario some compression garments, used in the treatment of lymphedema, are partially covered by the Assistive Devices Program (ADP) but there is very limited coverage for treatment of lymphedema. We are making targeted efforts to change this and encourage the Ontario government to cover treatment that helps maintain a patient's quality of life. We need



support to help raise awareness and advocate for lymphedema patients and their loved ones. If you are interested in volunteering or donating contact us at info@lymphontario.ca.

“I am so thankful to the Lymphedema Association of Ontario as through the webinars I have learned so much more about my condition!” - Doreen

THE COMPASSION FUND

The mission of the Compassion Fund is to provide financial assistance to patients who cannot afford the necessary treatments. The goal is to allow patients to work with a professional practitioner to assess their condition and learn how to manage and care for their lymphedema. We raised money in the fall of 2020 for the Compassion Fund. To date we have assisted 11 patients, one of whom told us, “it is vital for me and others to have access to this fund.”

For more information visit <https://www.lymphontario.ca/Compassion-Fund-Application>



Lymphedema

Frequently Asked Questions

What is Lymphedema?

Lymphedema is a chronic, inflammatory condition and is characterised by chronic swelling that can occur in any area of the body. It is usually in the head or neck, the genitals, the chest wall, breast or limbs.

What causes lymphedema?

Any condition that can overwhelm the lymphatic system. There are two types of lymphedema, primary, which is hereditary and secondary which can be caused by obesity, venous disease, cancer treatment (Lymph node dissection, radiation), trauma, immobility, infection and surgical intervention.

What are the signs and symptoms of lymphedema?

Some of the signs include heaviness, aching and swelling.

What are the potential complications of lymphedema?

Complications include reduced mobility, cellulitis, chronic pain, psycho-social impacts and limited activity of daily living.

Can lymphedema be treated with medication?

It cannot be treated with medication, although this is being researched. Antibiotics and anti-fungals are used to treat cellulitis, a bacterial infection of the skin which lymphedema patients are susceptible to.

What is the gold standard for treating lymphedema?

A treatment called Complete Decongestive Therapy (CDT) which includes Manual Lymph Drainage (MLD), skin care, exercise and healthy eating and compression therapy.

Is there a cure for lymphedema?

There is no cure for lymphedema but research is being done in a number of areas including surgical intervention and medication.

What will happen if someone does nothing with their lymphedema?

Lymphedema is a progressive condition. If left untreated the swelling may become much worse and over time the risk of cellulitis infections will increase.

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Prevalence of Lymphedema for Canadians

	Canada 1 million for 36 million population*	Ontario 388,920 for 14 million population**
Chronic Venous Insufficiency: Undetermined		
Morbid obesity related	570,000	221,684
 57%		
Cancer related	310,000	120,565
 31%		
Disabilities/chair-bound	83,000	31,114
 8%		
Surgeries (non-cancer)	40,000	15,557
 4%		
Primary lymphedema	20,000	7,778
 2%		

Mean incidence of cancer related lymphedema from systematic reviews

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

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

A WORD FROM OUR PRESIDENT

Advocacy is the number one priority in the Lymphedema Association of Ontario’s Strategic Plan, and it is as important as ever at this challenging time. World Lymphedema Day offers us a unique opportunity as a global community to advocate for lymphedema patients around the world to make cures for lymphedema and Lymphatic disease a global priority.

- Dolores Steinwall



Actions for World Lymphedema Day

We have a number of initiatives planned this year. We are partnering with outside agencies more than ever before



Launching a Virtual Support Group

Ten of our member therapists have volunteered to host a Virtual Support group for patients. We will launch the support group the first week of March.

Events with partner organisations

Our President, Dolores Steinwall will speak at a patient event at Sunnybrook Health Sciences Centre where she will share her story, from cancer survivor, with a diagnosis of secondary lymphedema to President of our provincial association. On March 4 our President Dolores and Board Director Ann DiMenna of Markham Lymphatic Centre will present a webinar about lymphedema for the Canadian Cancer Survivor Network (CCSN). We will be connecting with a number of organizations to raise awareness and advocate.

Declarations of World Lymphedema Day

Last year four Ontario cities declared World Lymphedema Day. Our goal is to expand that and in doing so raise awareness.

MPP letter campaign

Members are invited to use our MPP letter template to write their MPP and ask for treatment funding for all patients in Ontario living with the condition.

Lighting up Ontario

We are requesting cities across Ontario light up buildings, like the CN Tower with our signature teal colour for World Lymphedema Day to demonstrate community support.

Sharing our stories

Our members will be sharing their stories on our website, social media, with local media and on the Canadian Breast Cancer Network (CBCN) blog.

Sharing your story

Tips to help you share your story effectively

Personalise your story

Put yourself in the place of the person you are communicating with, what is going to make your story interesting, what is your hook? Imagine you know nothing about lymphedema. What is important to include? Refer to the information in this kit for facts you may wish to include.

Do a little homework

Find out what the deadline for the media or organisation you are working with. World Lymphedema Day is Saturday, March 6 and it would be best to have your story released in the week preceding March 6 or on that date.

Follow up

After you have made your pitch, whether by phone or email follow up. Find out the best time to contact them and discuss your story. Make yourself available for them and follow up promptly when they respond.

Be knowledgeable

Prepare in case the person you are communicating with wants to interview. Have your advocacy kit handy and be ready to speak to the issues.

Highlight the important points

Lymphedema has physical, emotional and financial challenges. Patient's feelings of well-



being may be affected, body image concerns, loss of mobility are all issues that may come with the burden of this unique condition. Emotionally concerns may include anxiety, fearing the future, concerns around infection and maintaining health. Financial challenges include the cost of treatment which has very limited coverage in our health care system in Ontario. Bandaging, the gold standard of treatment, is not funded. Some insurance companies do not cover, or only partially cover garments, therapy and pneumatic compression pumps. We are working with our MPPs to petition for funding that will support education and treatment of lymphedema.

Help is available

You are not alone in this. If you need assistance contact Janet at volunteer@lymphontario.ca

