Lymphedema Matters Association of Ontario

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To New Beginnings

While the awareness of lymphedema increases its reach across the globe, as evidenced by the second annual World Lymphedema Day on March 6. our new LAO Board and Advocacy committee are working diligently to create a clearer picture of how the chronic condition of lymphedema affects those in our province.

As a first step, we formulated and distributed a short survey to our listed provincial lymphedema therapists, asking them to inform us about the numbers and variations of the lymphedema conditions they are seeing in their practices. The information being requested has been strictly limited to trends in numbers and variations; there are no aspects of the information requested that identifies individual clients.

To our knowledge, trying to establish a provincial picture of these trends has not been done recently, and it is the sincerest hope of our new LAO Board of Directors that in 2017 we can begin to create a more accurate

understanding of the overall nature and extent of lymphedema in the province of Ontario.

We recognize that the LAO is an important provincial resource for support and information to assist those living with lymphedema, and we strongly desire to establish ways to best help Ontarians who are living with this chronic and difficult condition, especially those who may be experiencing significant struggles.

The survey was first sent out to 75 therapists on December 1, 2016. The responses poured in weekly, and the data trends emerging are both interesting and enlightening. These responses are the first step in the right direction to creating an understanding of the prevalence of lymphedema in the province.

At the time of this publication proceeding to print we continued to receive therapist responses. We look forward to sharing further updates as we begin to shape this data and formulate next steps.

We also wanted to share that we recently held a half-day strategy workshop with our board to discuss realistic goals and objectives for the coming year, to guide us in charting the best course moving forward and to provide value to our members.

The energy of our group is contagious and our session ran an hour over schedule as we had so much to passionately discuss. We are actively planning our next events, including our AGM and Awareness Walk which we plan to host again this Fall. Another one of our next steps is to create another survey to engage with our members and the lymphedema community to learn more about how we can support you as a provincial organization. We want to hear from you! If you have any ideas you'd like to bring forth for this outreach to the larger provincial community, please contact us at info@lymphontario.ca.

By Debbie Ciotti-Bowman and Liisa Morley

LET'S GET PUMPED

Manual Lymphatic Drainage and Compression Pumps

Manual Lymphatic Drainage (MLD) has proven to be very successful in the treatment of lymphedema. Unfortunately, due to lack of adequate funding, this form of specialized treatment cannot be easily obtained or administered as frequently as required to maximize results. Millions of patients around the world continue to suffer in silence due to lack of access to treatment of this rapidly growing health problem.

Thanks to continued research into lymphedema treatment and recent advancements in technology, compression pumps are proving to be an effective form of complimentary treatment to help increase availability and effectiveness of MLD treatment programs for those in need.

Pilot Pump Project

In September 2016, a Burlington, ON Wellness Clinic started to pilot the use of sequential compression pumps in combination with a regular MLD therapist treatment program.

"By introducing the use of a compression pump along with regular MLD treatments, we have seen accelerated reduction of limb size at a much faster rate, especially during the initial treatment reduction phase," shares Kim Gladman, owner and principle MLD Therapist at Head to Foot Oasis.

To date, the results illustrate that pumps are a valuable addition to the Combined Decongestive Therapy (CDT) regime and better still, because of their portability, patients can use them in the comfort of their home in between MLD treatments to maximize the benefits.

This approach not only allows patients to participate more in their treatments, but also gain a larger sense of control over their condition.

One patient stated that, "having the use of a pump at home means I no longer have to deal with dramatic fluctuations in swelling in between my MLD therapist treatments, and I feel like my therapist and I are winning the battle against my condition."

Another patient simply stated, "the pump allows me more flexibility with my schedule and that makes life much easier living with lymphedema."

Case Study

Background

The personal goal of this specific patient was to purchase a non-custom wrap for her arm. Upon assessment, the patient's arm was too large to purchase an off-the-shelf Velcro wrap.

The client presented with significant fibrosis in her arm, limited range of motion and reported pain rated as 7/10 on the Visual Analog Scale (VAS).

Study Goal:

 To treat the patient using traditional CDT (MLD and bandaging) and adding the compression pump at home daily to accelerate the treatment phase of lymphedema and reach goals safely and effectively.

Treatment Goals:

- To reduce edema and allow client to wear a non-custom reduction garment.
- To improve range of motion by 30%, (flexion of her arm was <90°).
- To reduce pain by three points on the VAS. (Pain was interpreted as heaviness and bruised).

Treatment Plan:

- Assessment and MLD treatment (one hour).
- Home care with use of Compression Pump (two times a day for one hour).
- Four MLD treatments of 45 minutes in duration to reduce fibrosis and monitor effects.

Treatment:

- Vodder Certified CDT therapist provided treatment to the client's neck, chest, left arm, and back to treat fibrosis, edema and pain in the arm.
- Four MLD treatments of 45 minutes every five days to reduce fibrosis and monitor effects.

Outcomes:

- See Appendix A (below)
- Improved range of motion of the left arm (>120°).
- Pain reduced by three points on the VAS. Client did not need assistance of her right arm to raise her left arm to approximately 125° flexion.
- Client's swelling reduced significantly in the four weeks of treatment. Approximately 13 cm in circumference reduction in the top of the arm. By the fourth week client was fitted in an "arm wrap" reduction garment that was off the shelf.

Follow up

Over the next two weeks, the client did not receive MLD treatment and did not perform self-treatment through use of the compression pump. When the client returned to the clinic for treatment her arm had increased by two cm in circumference and the heaviness was returning.

This individual case study supports the combined treatment plan of MLD, bandaging and compression pump therapy in expediting the treatment phase of lymphedema. It also reinforces the fact that once reduction goals are achieved, maintenance of the mentioned treatment plan is critical. Lymphedema is a chronic condition that needs to be addressed on an ongoing basis.

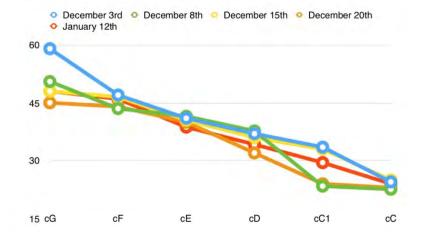
If a client has stage one lymphedema (also known as mild edema) this may not be the case, but if the client has lymphedema it is critical to find a certified lymphedema therapist who will work with them to establish the best treatment plan to suit their personal needs.

Head to Foot Oasis will continue to document the effects of this combined therapy to substantiate the use of both modalities.

By Kim Gladman

Appendix A Client Case Study Dec 3rd 2016 - Jan 12th 2017

Area of measurement	December 3rd	December 8th	December 15th	December 20th	January 12th
cG	59cm	50.5cm	48cm	45cm	48cm
cF	47cm	43.5cm	46.5cm	44cm	46cm
cE	41cm	41.5cm	40.5cm	40cm	38.7cm
cD	37cm	37.7cm	36cm	32cm	34.2cm
cC1	33.5cm	23.4cm	33cm	24cm	29.5cm
cC	24.5cm	22.6cm	25cm	23cm	24cm



DID YOU KNOW? Compression pumps are covered through the Government of Ontario's Assistive Device Program (ADP) for patients diagnosed with Primary Lymphedema. You can also check for coverage through your extended health plans.

Head to Foot Oasis offers sequential compression pumps for purchase or rental and have on-site certified fitters for a range of compression garments offered through ADP.

For those with limited coverage, or for flexibility in your treatment options, the clinic offers a 30/30 treatment option that allows the client to have 15 minutes of hands-on MLD therapist treatment to engage the lymphatic flow and redirection, followed by a 30 minute session on the pump, and ending with 15 minutes of MLD therapist treatment to ensure that lymph is cleared from the affected area. This treatment is offered at a reduced price compared to a full hour of MLD and is showing promising results in the effective treatment and/or maintenance phase of lymphedema.

For more information, or to evaluate whether a compression pump could work for your personal treatment plan, contact Head to Foot Oasis for a complimentary 20 minute trial at 905-332-6542 or www.headtofootoasis.ca.

Do you have an important story to share with the lymphedema community? Consider sponsoring an advertorial in a future issue.

Thank You to Diane Lieder and Ladies!

This past November, Diane Lieder organized a Ladies Night Out to raise funds for the LAO.



Diane Leider (right) with friend Cindy

With the help of sixteen friends who each donated raffle items for a live auction, a 50-50 draw and a few individual donations, Diane and her friends raised \$620 for the LAO!

"I had a display table with information, as well we sold butterflies made out of paper that people could write their names on and hang on a small lit tree," says Diane.

Just prior to the event's intermission, Diane shared a brief speech highlighting her thoughts on living with lymphedema.

"I feel we need to raise awareness of this condition so that doctors and those in the medical field can provide more information, as well as making access to treatment easier. Many people were interested in learning more. It was also the first night many people learned of my condition," she shares.

Coming to acknowledge that you live with a chronic condition can be very challenging, and sharing it with others can be even more difficult. We want to thank Diane for her courage in sharing her personal story, and want to give a shout out to her amazing group of supporters and friends! On behalf of all of us here at the LAO, thank you for your support and role in helping to share awareness. You are not alone.

If you'd like to learn more about how you can help spread awareness and raise funds for the LAO by hosting a third-party event, please contact us at info@lymphontario.ca.

LymphedemaAssociation of Ontario

Please be aware of our **new mailing address:**

3044 Bloor St. W., Suite 299 Toronto, ON M8X 2Y8 Canada

info@lymphontario.ca 416-410-2250 | 1-877-723-0033



In Ontario, the *Pathways* magazine and the *Lymphedema Matters*newsletter insert are distributed by the Lymphedema Association of Ontario

THANK YOU to our 2016 AGM&Walk Event Sponsors

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Plan on Joining Us this Fall for the LAO 2017 AGM & LE Awareness Walk!