



Lymphedema Matters

Association of Ontario

Summer 2019 | Ontario Resources

Volume 22 Issue 3

Advocacy Update: A Very Busy Quarter!

This last quarter has revealed a wider effort in networking and collating of survey results. As a result, the LAO has achieved a new level of advocacy on behalf of all those living with lymphedema in the province of Ontario.

In addition to participating in various awareness and education events associated with Lymphedema Awareness month, LAO representatives also entered Queen's Park to speak with Members of our Provincial Parliament (MPP).

As a result of our Advocacy Chair networking with the Canadian



Debbie Ciotti-Bowman (Advocacy Chair) meets Minister Christine Elliott at Queen's Park

Cancer Survivor Network, LAO representatives were invited to an Ontario legislative breakfast reception on February 20th, 2019. This platform allowed for discussion on the problem of lymphedema in Ontario with MPPs, and other individuals who work to raise awareness of healthcare issues at the provincial government level.

Beyond discussions with our MPPs, LAO representatives briefly met Minister Christine Elliott, in order to personally express our interest in a future meeting with her, so to further the narrative on lymphedema, derived from all causes, in Ontario. Minister Elliott expressed interest and openness to this request.

The LAO group was then invited to attend the "Question and Answer" period that followed the reception. How brilliant it was to hear the Lymphedema Association of Ontario being introduced to the entire Legislative Assembly by Burlington MPP, Jane McKenna, that morning!

LAO Advocacy efforts are indeed strengthening and expanding!

Although this is a time of great change in Ontario's healthcare system, there may be opportunity in this shifting paradigm to promote an improvement in healthcare delivery to Ontarians with lymphedema,



Tony Wight, Catharine Bowman, Jackie Manthorne, Jodi Steele, Debbie Ciotti-Bowman, and Jaclyn Jones

though we realize change is often slow. Our first Queen's Park event, and upcoming plans and invitation to return to Queen's Park, give us all hope that we will be able to bring much improved understanding of the lymphedema community to our provincial government in the very near future.

Please stay tuned to hear, and read, about our continued advocacy efforts!

By Debbie Ciotti-Bowman ■

Creating an Informed LAO Advocacy Platform: A Summary of Ontarians' Experience with Lymphedema

The results from the most recent poll, made available for Ontarians with lymphedema or their caregivers and therapists, are compiled after a year of collecting data. Selected insights are shared in the summary below.

This current report builds upon the previously illustrated dynamics of 2686 anonymous Ontarians treated by certified therapists in 2017. These results assist the LAO to strategically advocate for the province-wide lymphedema population.

Thank you to all those who generously took the time to further contribute to our understanding of lymphedema from the perspective of patients, caregivers or therapists.

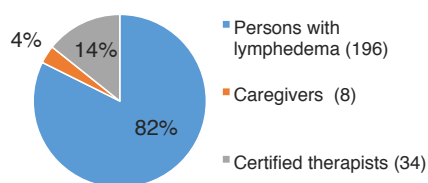


Figure 1 Respondent Demographics: There were 238 respondents. Notably, several individuals identified with more than one category relating to lymphedema.

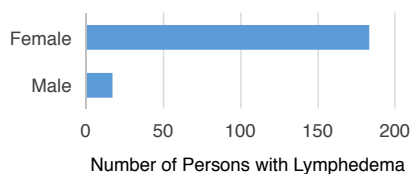


Figure 2 Sex Distribution: There were 17 males and 183 females identifying as having lymphedema. This distribution describes a substantially lower number of males reporting lymphedema, similar to the results of the 2017 Therapist Survey. The increased proportion of females may be accounted for in part by the greater number of females experiencing breast

cancer related lymphedema. However, the large difference between males and females warrants further exploration in order to fully understand the impact and mechanism of this difference.

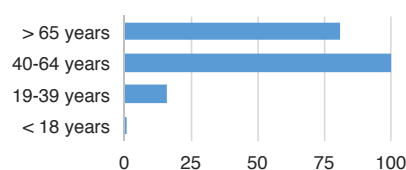


Figure 3 Age Distribution: Responses indicate lymphedema affects individuals over a wide age range. Similar to the 2017 Therapist Survey, the greatest proportion of affected individuals lies within the 40-64 yr old age range.

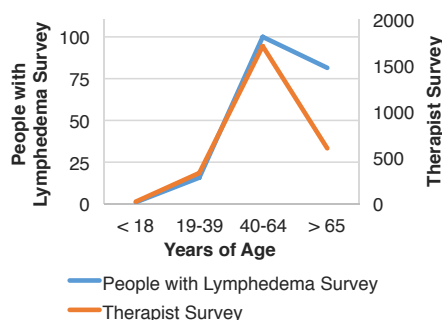


Figure 4 Relative Differences in Therapist Survey and People with Lymphedema Survey: Illustration of the numbers of individuals with lymphedema across age groups, from both the 2017 and 2018 responses. Interestingly, a similar pattern of distribution is exhibited between the first 3 age groups, when comparing both 2017 and 2018 results.

However, Therapists in 2017 reflected a 65% drop in the number of clients they treat who were older than 65 years of age, while the 2018 persons with lymphedema (or their caregivers), self-reporting the condition, indicated lymphedema experiences in ages up to 86 years. Thus, the graph of the 2018 group shows only a 19% drop after

65 years of age. Comparing the 65% drop in the number of clients being treated by therapists for lymphedema after 65 years of age to the much smaller drop in the number of those who are self-reporting lymphedema experience after 65 years of age may indicate further support for the concern that fixed income or lack of private insurance in this age group may be an obstacle to obtaining therapy. The concern regarding access to therapy in this age group warrants further exploration.

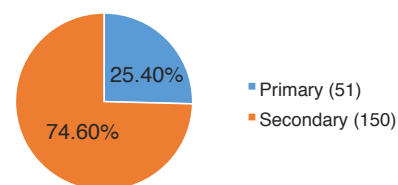


Figure 5 Lymphedema Type Distribution: Approximately 74.6% (150) of respondents indicated experiencing Secondary lymphedema related to multiple causes such as vascular problems, trauma, obesity or cancer-related treatment. Cancer-related treatment was most commonly reported. 25.4% (51) of respondents indicated experiencing Primary lymphedema. This is a similar percentage breakdown of Primary and Secondary lymphedema as the 2017 reports of types of lymphedema in clients being treated by provincial Therapists.

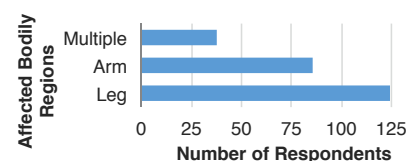


Figure 6 Lymphedema Affected Regions: Responses indicated more leg regions affected by lymphedema than arm or other bodily regions.

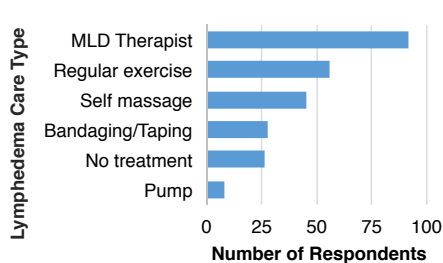


Figure 7 Lymphedema Care Strategies Utilized:

When asked which care strategies respondents use to manage their lymphedema effectively, respondents often indicated a combination of strategies. It is important to note that a small number of respondents had accessed lymphedema pumps. The lymphedema pump is reimbursed by Assistive Devices Program Ontario for those who qualify with a diagnosis of Primary Lymphedema and a doctor's prescription, to optimize their self-care.

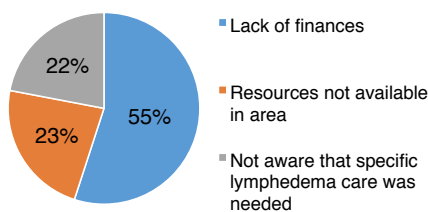


Figure 8 Finding Care Resources: Of 197 respondents to the question "Are you able to find the care you need to be able to effectively manage and control your lymphedema?", 54.8% indicated that they can find resources for their care. However, 45.2% of respondents indicated that they cannot find resources for their care. Of this latter group, 55% indicated lack of financial resources for care. Further, 23% indicated lack of treatment resources in the geographic region in which they live and 22% indicated they did not know specialized care was required for their condition.

Of the 139 respondents who described cancer treatment as the cause of their lymphedema, 51% indicated it was not explained that lymphedema might be a side effect of their necessary treatment. This insight suggests important implications for cancer care that facilitates timely patient

education and the support of cancer survivors who experience this chronic condition.

Regarding experience with cellulitis related to lymphedema that required medical treatment, 198 respondents answered this question, with 42.9% indicating experiences with cellulitis related to their lymphedema requiring antibiotic treatment.

Lastly, across 187 responses to the question: "Do you have private coverage for treatment costs or other methods to cover medical costs?", 63.7% indicated they have private insurance coverage for treatment costs or other methods to cover lymphedema medical costs.

Conversely, 36.3% indicated that they do not have any private insurance to reimburse their healthcare costs relating to their lymphedema care.

Importantly, the majority of those reporting private insurance for treatment costs further indicated inadequate insurance reimbursement for Manual Lymphatic Drainage or other equipment or supply costs beyond the Assistive Devices Program subsidy for compression garments. Further, respondents about to retire indicated great concern about not having adequate, or any private insurance to cover their lymphedema care costs when they are retired from their occupations.

The question: "What lymphedema related issue do you feel is most pressing in Ontario?" revealed that the vast majority of respondents, across all categories, indicated that a lack of funding and equal access to appropriate care for those with the chronic condition of lymphedema is the most pressing concern in Ontario.

Other most commonly noted concerns in those living with lymphedema:

- Concerns expressed that there is a need for timely education and therapeutic care for persons who may be at risk, or who have developed cancer-related or other forms of lymphedema, in order to minimize the long term impact of lymphedema.
- The great difficulty associated with accessing a doctor to diagnose the condition and the shortage of Ontario

specialists knowledgeable about the condition to provide medical direction to lymphedema patients.

- The need for improved education of healthcare providers about the lymphatic system, lymphedema and lymphatic disorders in order to improve their ability to recognize and understand this condition in their patients. This includes the need for understanding that lymphedema is a chronic condition and the need for a greater sense of urgency around this condition.
- The lack of training for surgeons in Canada for lymphatic reconstructive surgery.
- The lack of awareness and recognition of Primary Lymphedema accompanied by the need for resources and funding for Pediatric (Primary) Lymphedema.
- Lack of early and timely diagnosis/ recognition of the disease at both the hospital and primary care levels.
- Expression of a need for care at cancer centers or a partnering of cancer centers and community care provision for lymphedema patients.

Other commonly noted concerns of Therapists treating lymphedema:

- Lack of care in rural areas and variability in access to service across the province.
- Lack of research to improve lymphedema care and treatment options.
- Concerns expressed regarding inconsistent lymphedema therapeutic training and practice standards.

The LAO Board expresses gratitude to those who took the time to offer perspectives and insights into living with, and treating lymphedema. This feedback illustrates some of the predominant challenging issues that influence those who provide lymphedema care and those who live with chronic lymphedema in Ontario. The LAO is progressively working to ensure these challenges become better known, as well as further studied and incorporated into advocacy efforts in Ontario.

By Debbie Ciotti-Bowman ■

Lymphedema Awareness Month, March 2019!

On March 6th, 2019, lymphatic disease advocates from around the world campaigned to mark a day of awareness for lymphedema (LE). The LAO prides itself on our commitment to helping people living with lymphedema through awareness initiatives, advocacy efforts, research collaborations, and community outreach.

This year the LAO held a booth at Princess Margaret Cancer Centre (PMCC) and had the honor of raising awareness for LE by informing and educating members of the community! LAO representatives spoke with health care providers and other members of the



Charlotte Schultz, Tony Wight (Awareness Chair), and Ana Stosic (Events and Communications Chair)

community in hopes of shedding light on an underrepresented condition. Diverse discussions led to a successful two-day campaign in efforts to raise LE awareness.

Further, this year the LAO had the honor of participating in, not one, but three awareness initiatives!

In addition to the LAO booth at PMCC, the LAO attended events at Guelph General Hospital and at Juravinski Cancer Centre in Hamilton!

A wonderful display was held on March 6th at Guelph General Hospital. Many aspects of lymphedema were discussed with the community, patients with lymphedema, and medical staff seeking more information on lymphedema!

In addition, Debbie Ciotti-Bowman (Advocacy Chair) also attended the excellent Lymphedema Education program held at Juravinski



Debbie Ciotti Bowman (Advocacy Chair), Jane Mical Cambridge RMT, and Millie Stewart, Certified Fitter.

Cancer Centre in Hamilton—during Lymphedema Awareness week. This event provided a thorough, and insightful, educational session with opportunity for those with lymphedema, or at risk of lymphedema, to learn about the condition and pose questions.

By Ana Stosic ■

Save the Date!
Sunday, September 22, 2019
3rd Annual
Lymphedema Awareness Walk
LaSalle, ON




Lymphedema Awareness Walk LaSalle, ON 2018


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