



LYMPH LISTENS

**A community based
report on living with
lymphedema in Ontario**



EXECUTIVE SUMMARY

Objective

The *LYMPH LISTENS* project, lead by a team with first hand knowledge of lymphedema, reached out to the community of lymphedema patients as well as those at risk to better understand from their perspective the challenges facing them and assess how best we could positively impact their quality of life. Through a grant from the Canadian Breast Cancer Foundation – Ontario Chapter, the Lymphovenous Association of Ontario conducted a needs assessment to identify the greatest gaps in servicing the needs of lymphedema patients and those at risk in Ontario. The results would help chart the roadmap of where the Lymphovenous Association of Ontario needed to be and the growth required to meet the changing needs of cancer survivors and other lymphedema patients.

Key learnings

There is a lack of standardized and comprehensive patient education material on lymphedema, a need for more lymphedema hospital based diagnosis and treatment centres, limited knowledge among the medical profession about lymphedema, the treatment options and support services available and there are not enough trained and certified lymphedema therapists to meet the growing number of patients.

Recommendation themes

Four key categories emerged as priorities in tackling the gaps identified: Building a comprehensive patient education strategy; strengthening our voice and partnership with the certified lymphedema therapist community; focusing on equipping medical professionals with better material about lymphedema, treatment options and support services and increasing advocacy efforts on behalf of patients for more hospital based lymphedema centres and reimbursement of lymphedema treatment options.

Conclusion

The lymphedema community is grossly underserved. With more and more cancer survivors demanding quality of life, the growing need for lymphedema education, support and management tools will only get stronger. We have an obligation to impact closing the gaps between the needs and services currently provided. The first step needs to be in raising the profile of this condition and a greater profile of the Lymphovenous Association of Ontario.



A DAY IN THE LIFE of BREAST CANCER RELATED LYMPEDEMA PATIENTS

After cancer treatment, a whole new set of challenges:

- **Accessing comprehensive information about lymphedema**
 - **the risk factors, treatment options, self management and support resources**
- **Locating someone qualified to provide a proper diagnosis**
- **Gaining access to a hospital based lymphedema clinic or treatment centre**
- **Finding a certified lymphedema therapist**
- **Managing the costs associated with treatment**
 - **manual lymph drainage therapy if not covered by insurance**
 - **bandaging and compression garments**
 - **finding out the costs are for the remainder of your life**
- **Navigating the process for compression garment subsidy**
 - **Finding an ADP garment authorizer**
 - **Finding an ADP approved garment vendor**
- **Handling the psychosocial and emotional impact**
 - **dealing with image concerns**
 - **reaching out for and accepting emotional support**
- **Educating family physician, friends and family members about lymphedema**



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CONTEXT

What is lymphedema

Lymphedema is a chronic condition that occurs due to an abnormal buildup of lymphatic fluid. While primary lymphedema is caused by abnormalities of lymphatic vessels, secondary lymphedema is caused by damage or blockage to the lymphatic system and is most often the result of cancer treatment such as lymph node removal and radiation. For breast cancer patients lymphedema occurs most often in the affected limb, but can also occur in the neck, breast and trunk. The accumulation of lymph fluid causes a wide range of effects that can include impairment of daily activities, due to swelling, pain and lack of mobility of the afflicted body part. Under treated lymphedema can lead to irreversible complications and further damage to the lymphatic system. For patients with lymphedema as well as patients at risk for lymphedema, daily management is required for life to avoid frequent hospitalization for infection.

Signs and Symptoms of lymphedema

Recognizing some of the early symptoms and starting treatment right away is the best way to manage the condition. Some of the signs are a feeling of heaviness, aching or tightness in the arm, persistent swelling, skin texture changes, decreased flexibility in the arm, hand or wrist, rings or bracelets feeling a bit tighter, or the arm tiring easily or feeling hot.

Treatment Options

The gold standard of treatment is a patient customized program known as Complete Decongestive Therapy (CDT). Certified lymphedema therapists provide therapy that includes manual lymph drainage (to reduce the swelling), compression therapy (to stimulate lymph flow and maintain the limb), specific exercises (to promote lymphatic flow) and essential skin care (to minimize the risk of infections).

Incidence Rates

Incidence rates of lymphedema are difficult to find in medical literature because of the lack of proper diagnostics and the variance of measurement standards. The common accepted incidence rate of lymphedema among breast cancer survivors in our literature review was between 25 – 30 percent. Lymphedema can occur anytime after initial cancer treatment and even up to 5, 10 or even 25 years after.



Lymphovenous Association of Ontario (LAO)

The Lymphovenous Association of Ontario was founded by a small group of lymphedema patients and their families in 1986 with a mission to improve the quality of life for those living with lymphedema. Its goals are to

- Increase awareness and education among patients, healthcare professionals and the general public of the condition and the precautions those at risk can take to prevent or at least delay the onset of lymphedema.
- Provide support services to those living with lymphedema.
- Work with government and insurance companies for improved coverage for treatment and care.

A volunteer based organization; it has grown to provide patient advocacy, public awareness and education and outreach programs and services to patients, lymphedema treatment professionals and other health care providers. Some of these programs include operation of a province wide ebased support service, a toll free telephone support and information line, an annual educational conference on lymphedema, a comprehensive website, facilitation of a monthly lymphedema support group and a 20-page newsletter called *Lymphovenous News* published three times per year.

Some recent examples of educational impact the organization has had in the community are participation in the annual Women's Health Forum in Toronto, creation and distribution of a "lymphedema emergency purse kit" for patients to carry with them at all times in case of infection flare-ups related to their lymphedema, development of an information "at risk" card targeting breast cancer survivors participating in cancer fundraising events such as CIBC run for the Cure and sponsorship and organization of educational seminars (Grand Rounds) featuring world leading lymphedema experts such as Dr. Horst Weissleder, from Germany, for Cancer Care Health Care professionals at Sunnybrook Regional Cancer Centre and the Juravinski Cancer Centre in Hamilton. These seminars were invaluable in creating awareness within the health care community about the risks of lymphedema among cancer survivors, proper diagnosis of lymphedema and the effect of Complete Decongestive Therapy, which includes manual lymph drainage, in the treatment and care of lymphedema.

A key feature of this organization's outreach is an annual lymphedema conference that is held each fall. This educational event brings experts on lymphedema together and is a unique opportunity for patients, caregivers, therapists and health care professionals to share their knowledge and experiences with lymphedema.



PROJECT SPECIFICS

Objectives

The objective for the LYMPH LISTENS project was to determine the priorities that would have the greatest impact on those living with and those at risk for lymphedema. Through funding received from the Canadian Breast Cancer Foundation – Ontario Chapter, it set out to gain a clear, objective and thorough understanding of what the needs were within the lymphedema community. The project goals were

- To learn more about how breast cancer survivors living with lymphedema in Ontario are currently coping with the disease and what programs, services and initiatives they regard as essential.
- To build a strong knowledge base by identifying, documenting and analyzing what services, support and educational material are currently available to breast cancer survivors, lymphedema patients and health care professionals working with lymphedema.
- To identify and document gaps between the community identified needs and the services and information available.

Project team

Knowledgeable representatives from key stakeholders within the lymphedema community were either on the core project team or as part of the steering committee. Moreover, many members of the core project team and/or steering committee are themselves living with lymphedema, providing the project team with a deeper understanding of the types of questions and fact finding they needed to focus on. We also had the services of a consultant who was experienced in market research within the non profit sector, and provided support on the questionnaires, focus groups, interview protocols, analysis and final summaries.

Lymphedema community stakeholders

The stakeholder groups contacted within the Ontario lymphedema community included:

- People already living with lymphedema
- Breast cancer survivors at risk for developing lymphedema
- Health Care Professionals likely to diagnose lymphedema (Clinical nurses, radiation oncologists, vascular surgeons)
- Health care professionals with post graduate training in lymphedema treatment and certified as lymphedema therapists (registered massage, physio, and occupational therapist, nurses)
- Compression garment vendors and fitters



Tools and Methodology

A guiding principle was to incorporate wide representation of the lymphedema community within Ontario to obtain qualitative data. We ensured our reach extended to suburban and rural areas, both large cities and small communities across the province where lymphedema patients and patients at risk were represented. We obtained feedback from 150 people (115 surveys, 17 focus group participants, 18 stakeholders).

We capitalized on the existing relationships, channels and networks created within the lymphedema community to recruit people to participate.

Surveys – Comprehensive surveys were administered to

- those currently living with lymphedema
- breast cancer survivors at risk for lymphedema
- Health care professionals and other key stakeholders working with lymphedema patients

Surveys were distributed at the 2005 annual lymphedema conference at Sunnybrook Cancer Centre in Toronto (to registrants who were either breast cancer survivors or health care professionals across the province), through lymphedema certified therapists, website invitations, *Lymphovenous News* advertisements and to lymphedema support group attendees. We were pleased with a survey response rate of 37%; much above our target. Survey results were recorded and graphed in an initial 20 page document.

Group Consultations - there were a total of 5 group consultations with 17 participants completed in both Toronto and London, at Gilda's Club, Wellspring and London Breast Cancer support groups. A laptop was used to document feedback at each session to create a transcript, resulting in 12 pages of recorded feedback.

Interviews - a total of 18 separate one hour interviews were conducted (with corresponding transcripts produced) by the project lead with representatives of the key stakeholders within the lymphedema community.

Literature Review

A review of existing services, literature and information available to breast cancer survivors and those affected by lymphedema was conducted.

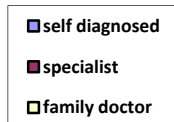
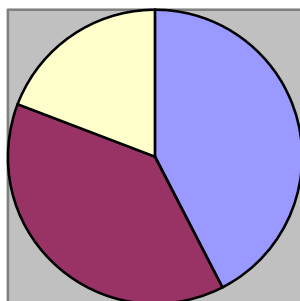


KEY LEARNINGS

Understanding our audience

Of the survey respondents, 92% were women, 84% had breast cancer before developing lymphedema, and 82% were aged 50 years or older. Of those surveyed, 80% have lymphedema in an upper extremity, 78% were treated with radiation as part of their cancer treatment and the average time between cancer treatment and onset of lymphedema was 3.2 years. The median time was one year (with the earliest time being 2 months and latest time being 15 years).

Initial lymphedema diagnosis



42 percent of the respondents told us that their lymphedema was self diagnosed or with the help of family members, friends or by researching on the internet

38 percent were diagnosed with lymphedema by a medical specialist

and only 19 percent received their lymphedema diagnosis through their family doctor.

Finding out about lymphedema

On the one hand 93% of people with lymphedema developed as a result of breast cancer treatment reported that they had *not* been told by any source (either their family doctors, surgeon or radiation oncologists) about the likelihood of developing lymphedema or what could be done to reduce the risk or delay the onset of the condition. Only 12% of respondents reported receiving information about lymphedema from *any* source after they were diagnosed with breast cancer.



Finding out about lymphedema – continued

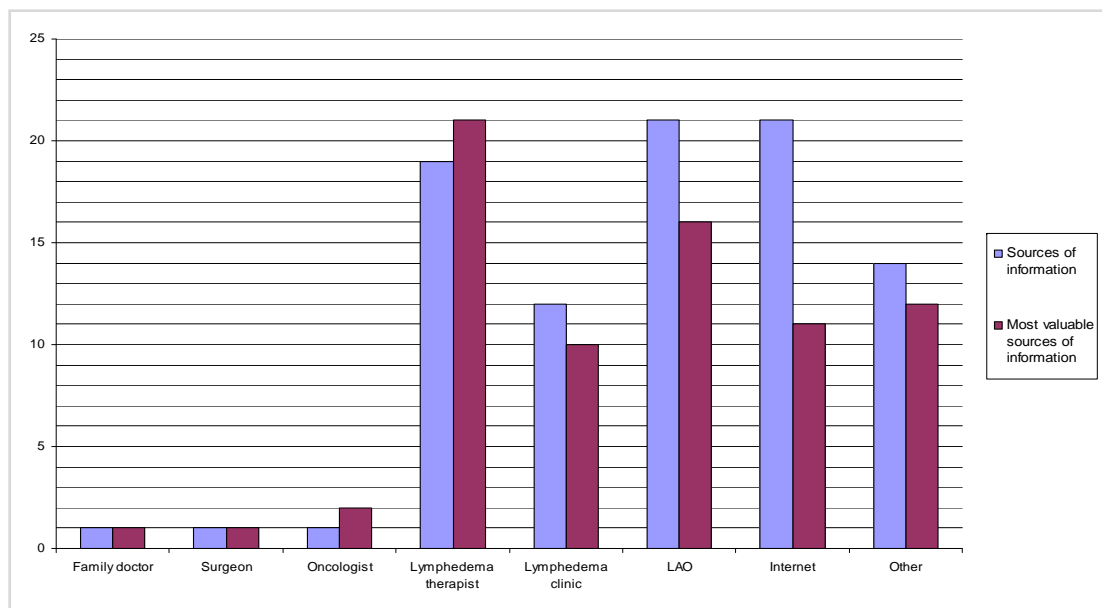
On the other hand most doctors/nurses we interviewed gave their perception that between 50 to 75% of patients *are* told about the possibility of the condition but that receptiveness and timing could be a factor since cancer patients are primarily concerned with more immediate issues such as cancer treatment and survivability. Another factor to consider is that that patients can be diagnosed with lymphedema many years after their initial cancer treatment and therefore any information initially received would long have been forgotten.

From the perspective of other health care professionals within the community, not more than 20% of patients are told comprehensively about lymphedema. At most their patients tell them that the focus of post operative information is on exercises but not the risk of lymphedema, what to do if it happens and where to go for treatment options. The risk of lymphedema was minimized; the implications of lymphedema ignored and many patients told it would only be temporary. The fact that lymphedema for the majority of patients is progressive was never discussed.

Patient Education

Sources of Information

After their initial lymphedema diagnosis, 70% of respondents reported that lymphedema therapists and clinics were the most important sources of information about the condition. In the longer term, the most valuable sources of information and support were also reported to be certified lymphedema therapists. This may be due to the ongoing contact that many people with the condition have with their therapists.

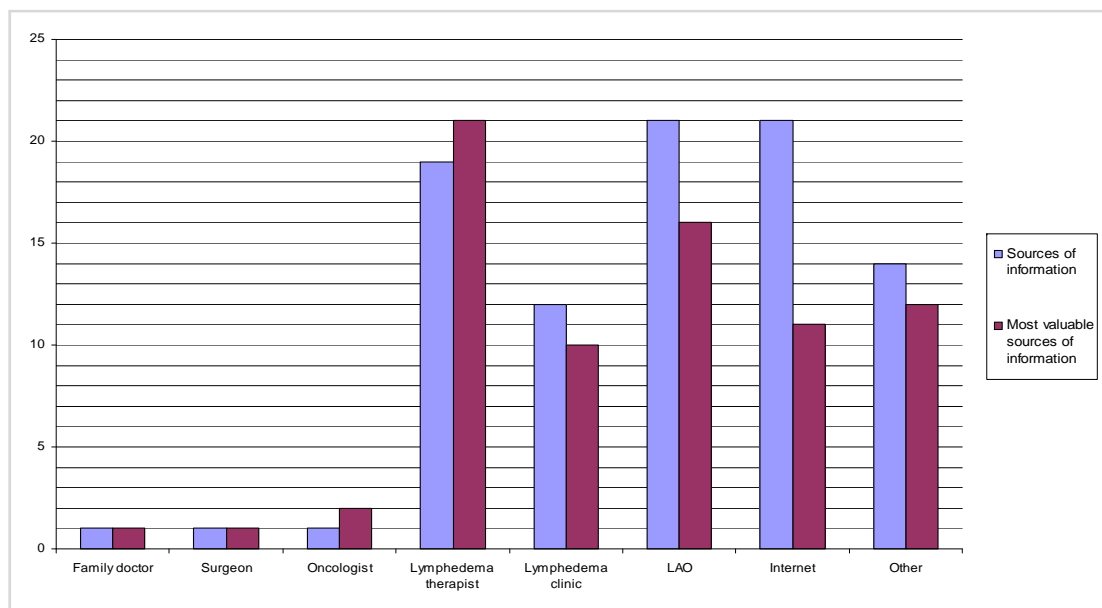


Sources of Information- continued

Other breast cancer survivors were left to investigate the condition on their own through the internet, available literature, local health organizations, and with the help of family and friends.

All health care representatives we interviewed agreed that all breast cancer patients *should* be told about the risk of lymphedema before their surgery to help make informed decisions about treatment options. There were various perspectives on what type of information and when it should be given.

The benefit of lymphedema education can't be stressed enough; preventing lymphedema or delaying the onset for those at risk and improving the quality of life for those living with lymphedema.



Level of knowledge about lymphedema

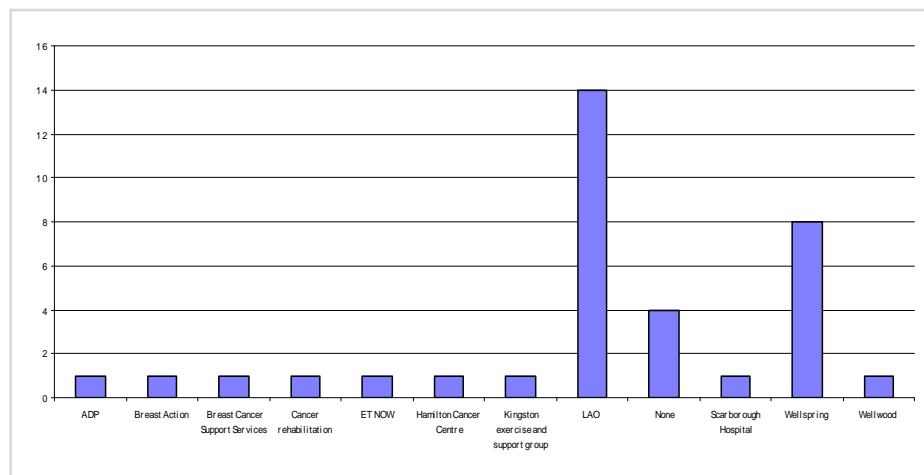
Most focus group participants could describe some of the basic symptoms of lymphedema yet were unable to list more than 3 precautions they should be taking. Furthermore there was a variance between those that knew of possible treatment options and those that assumed there was nothing that could be done once you got lymphedema. A concerning discovery was the perception among many Breast Cancer survivors without lymphedema, that they had been lucky to “escape” the condition and were now risk free. The *lifetime* risk of lymphedema was not clearly understood.



Organizations and community service agencies that have directly helped people cope with lymphedema

The majority of people participating in the surveys or focus groups knew about the Lymphovenous Association of Ontario and Wellspring, available to help them cope with lymphedema. However, these questions followed an introduction on the organization and therefore aren't indicative of the awareness in the community of the LAO.

The majority of respondents reported that the LAO has helped them by providing information through the newsletter, their support groups, and the annual conference and by informing them of certified therapists and compression products.



Treatment and therapies

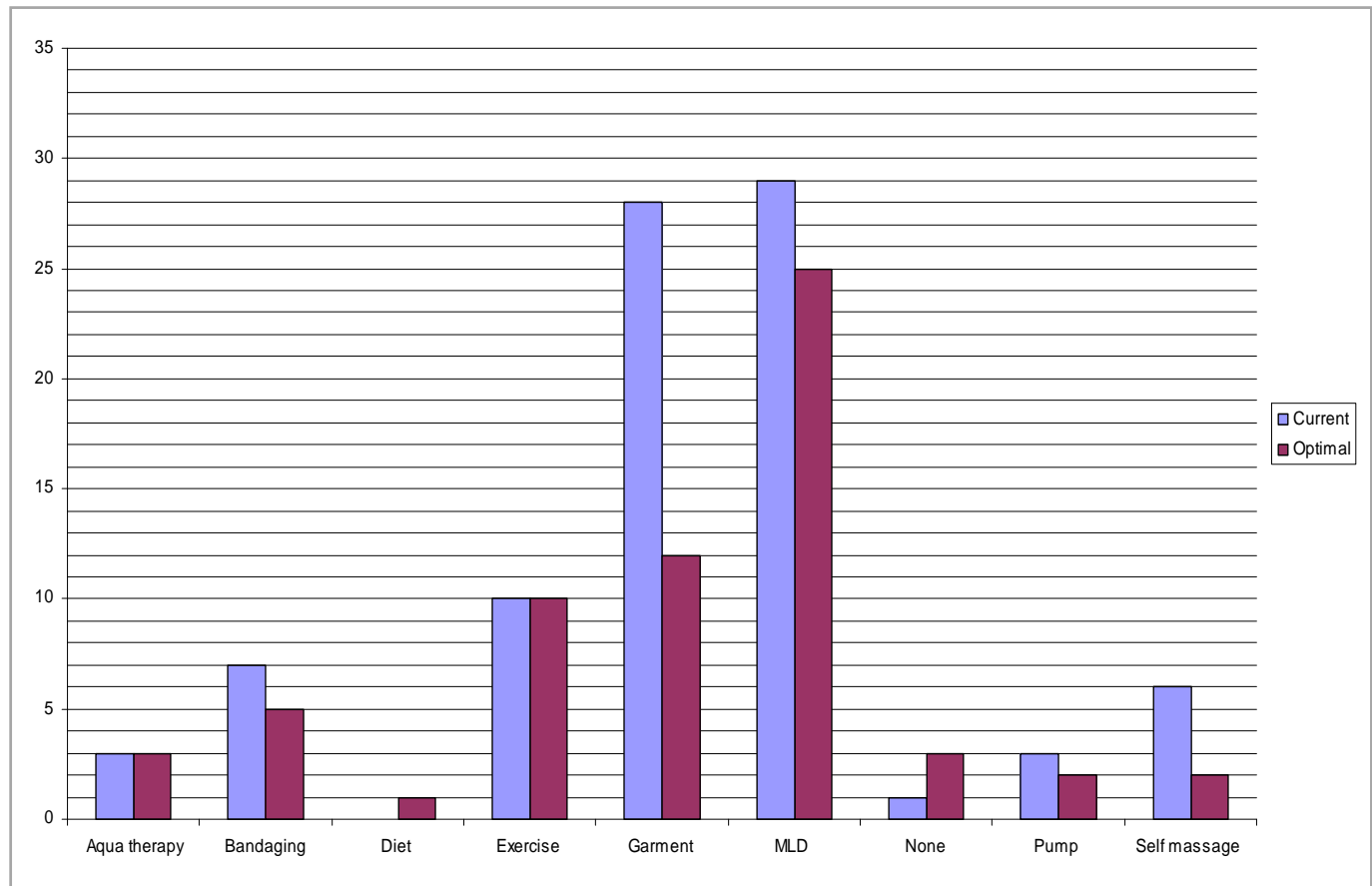
Patients reported to us that manual lymph drainage and the use of special garments were the most commonly used treatments for lymphedema (by 70% and 68% respectively) yet these treatments are not actively endorsed by all doctors. When asked what treatments would be *optimal*, respondents indicated a far lower preference for using garments (29%) - this response may be influenced by a number of interrelated factors unrelated to the efficacy of using garments: cost, discomfort, and self-consciousness.

We were told that low rates of compliance for compression garments are common among breast cancer survivors who develop lymphedema. Because the garments are worn on their arms, they are difficult to hide, may inhibit movement and are a daily reminder of their cancer.



Treatment and Other Therapies – continued

Other treatments that lymphedema patients were using to manage their condition included exercise (including the Lebed Method) and yoga (24%), bandaging (17%), self massage (14%), aqua therapy (7%), and pneumatic pumps (7%).



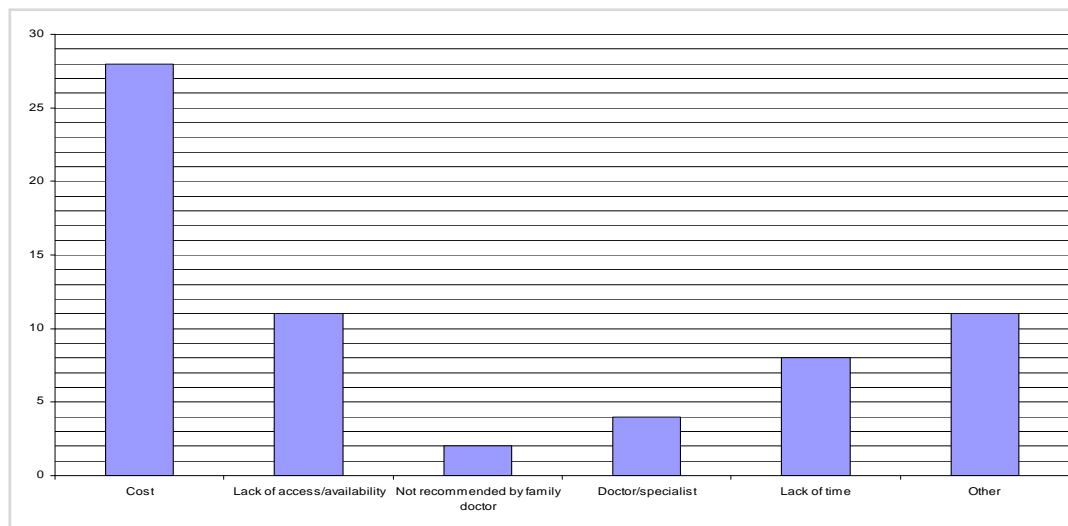
Barriers to effective treatment options

Unlike most other health conditions in Ontario, people with lymphedema indicated that cost is the most significant barrier to accessing the combination of treatments that are needed (in perpetuity) to cope with the chronic condition. Accordingly, respondents reported that almost all therapies involved expenses that are not covered by OHIP or personal insurance. The high cost of lymphedema therapy and compression products means that many people with the condition simply may not be able to get the treatment they need. The cost of treatments is likely an even bigger issue for older people, many of whom may live on fixed incomes (more than 50% of respondents were older than 60 years of age) and also don't have insurance coverage.

Although the Ministry of Health covers 75% of the annual cost of eligible compression garments under the Assistive Devices Program, 50% of the patients we spoke to were not aware of this provincially funded government program. Of those that were aware, both patients and health care providers told us that the process for reimbursement is deemed very cumbersome with a lot of paperwork. Finding both ADP appointed authorizers and vendors is challenging because there are so few. As an example, lymphedema patients from Hamilton must travel to Toronto for their garment fittings and many Lymphedema Certified Therapists are not authorized by ADP to provide the signatures on the authorization forms for their patients. Vendors we spoke to who supply the garments shared with us that there is little profit in supplying compressions garments; especially the customized variety and they deem the process as well to be filled with bureaucratic paperwork. This is a deterrent in new vendors or authorizers willing to get approved by ADP and supply these garments.

Finding a trained therapist and taking the time to go for hourly treatment sessions were other barriers for patients to seek treatment.

Health Care providers advised us that besides costs, lack of knowledge from physicians played a great role as well. Patients continually tell them no doctor ever told them that there were treatment options available. The biggest barrier for patients getting appropriate treatment may well be knowing there are treatment options and professionals specialized in lymphedema therapy.



The high cost of treatment therapies and products

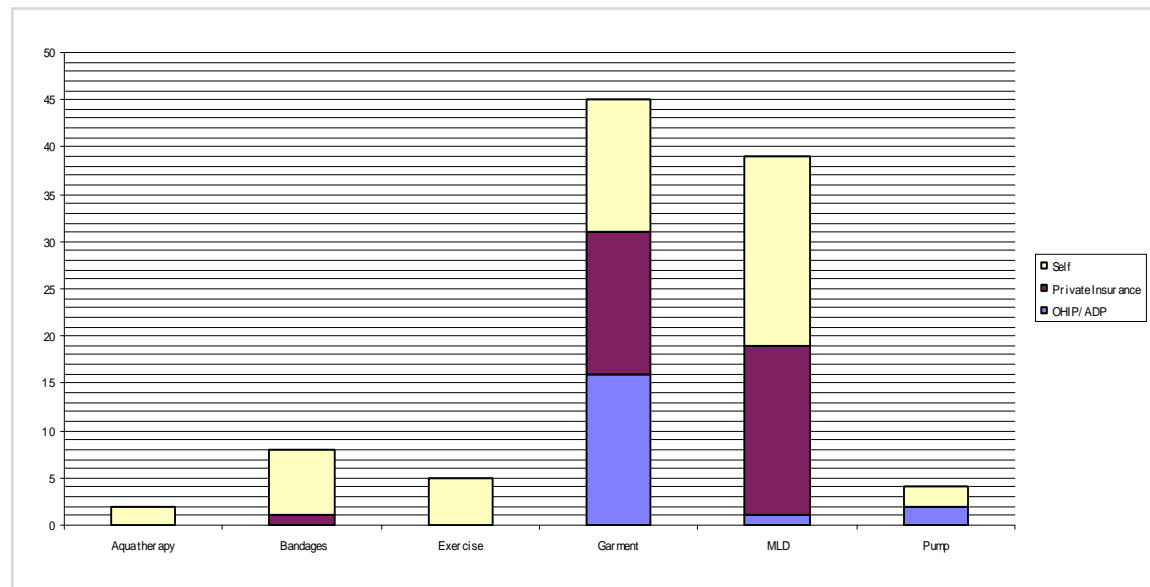
The costs associated with managing lymphedema can be very high. Upon initial diagnosis of lymphedema, the recommended intensive phase of Complete Decongestive Therapy includes therapy several times a week for at least four to five weeks. At an average cost of \$75.00 per hour, this phase can easily add up to \$1000.00. Ongoing treatment for maintenance on a monthly basis costs approximately another \$900.00 - \$1000.00 per year. There are additional costs for the compression bandages used in conjunction with CDT and the compression garments are costly, need to be replaced every few months and are only partially covered by the Assistive Devices Program. For some patients that aren't able to bandage or don't find relief through night time bandaging, an additional expense is a night time compression device that can cost up to \$4000.00 (also covered at 75% by the ADP program).

Payment of treatment therapies and products

Compression garments and Manual Lymph Drainage treatment factored the biggest costs for lymphedema patients. Just over half of the lymphedema patients we spoke to didn't have group or private insurance and paid the cost of MLD therapy out of their own pocket.

Since 75% of the cost of compression garments are covered under the Assistive Devices Program of the Ministry of Health and Long Term Care, we were surprised to see that 2/3 of the respondents indicated their garments were paid for by their insurance or themselves. We considered two factors;

- Many people didn't know about the ADP program and reimbursement procedure
- People could have been referring to the fact that the residual 25% of the cost of garments are being paid by themselves or insurance



Insurance Support

Most group and private health insurance programs in Ontario do provide reimbursement for the cost of compression garments. Actual payouts vary depending on contract variables such as deductibles, co-insurance and plan maximums. As an example, the majority of companies we contacted did cover the cost of compression garments if the doctor's prescription includes the diagnosis and the grade of compression prescribed of at least 20 + mmHG. The number of garments included in the coverage averages from 2 – 4 pairs per calendar year.

Manual Lymph Drainage therapy treatment is not recognized by most insurance companies, however many will cover the treatment if submitted as a treatment session by a physiotherapy, occupational therapy or registered massage therapists. There is generally a maximum amount allowed per year. When the manual lymph drainage is performed by a certified lymphedema therapist who is a private nurse, we were told that most insurance companies will not reimburse.

Accessing care - diagnosis and treatment of lymphedema

People with the condition are not always able to access lymphedema specific clinics or specialists at hospitals or local health centres due to poor hospital funding, and/or the programs don't have adequate promotion or profile. The risk for secondary lymphedema happens primarily within the hospital; therefore there is a strong view among health care providers we spoke to that hospitals should have a greater role in supporting patients with lymphedema. Lymphedema diagnosis and initial treatment needs to be embedded in every cancer centre in Ontario so patients can be equipped with the proper tools needed for their self-care. Yet there are a limited number of lymphedema centres to service all of the patients in Ontario. Some patients told us they were waiting almost 5 months for a referral to a lymphedema specialized nurse in the Cancer Centre. Primarily due to funding constraints, many of the clinics have no choice but to restrict their acceptance of lymphedema patients to either primary lymphedema (those that have contracted lymphedema since birth), secondary related only to cancer or just to people living within a certain encashment area of the hospital. Many hospitals will only see a lymphedema patient if they were originally a cancer patient at the same hospital. These policies have implications for patients in outlying areas and those that develop lymphedema several years after their initial cancer and are no longer in the follow up care of an oncologist or surgeon. The reason two hospitals have fairly recently created comprehensive programs for lymphedema patient care is primarily due to petitions and pressure from patients and physicians for the need to provide continued support for cancer survivors. In other cases, firmly established lymphedema clinics within a hospital have been terminated simply because the specialized person left the hospital and a qualified replacement was not found. Even where hospital based clinics do exist, the focus is on lymphedema diagnosis, measurement and education, not treatment.



Shortage of MLD trained therapists

For patients that can afford Manual Lymph Drainage therapy, many living in outlying areas reported travelling quite far to see a lymphedema trained therapist. However even within a large city like Toronto there are a fairly small number of therapists to serve a large population. Under the Vodder website, there are only 45 certified lymphedema therapists listed in Ontario. Many of these don't accept new patients as their workload is already overwhelmingly full.

One of the biggest deterrents for new therapists getting certified to practise Manual Lymph Drainage seems to be the high cost of training (an average of 160 hours of post graduate training for recognized certification). Costs include not only the course fees, but the travel expenses (not many training sessions are offered in Ontario) and time away from their current practices. There are currently no incentives or health care dollars provided to further education for those in private practice.

An isolated field of practice

A recurring theme we heard from our interviews with lymphedema practitioners was the lack of formal or informal networking opportunities for them to share their work on supporting lymphedema patients. Many provided comments that they felt very isolated in a distinct narrow field and that they would greatly benefit from collaboration on best practices, case studies and patient specifics.

Role of the Health Care system

90% of the health providers we surveyed stated that our health care system should take responsibility for the diagnosis, treatment and patient education of lymphedema patients. Since lymphedema is primarily related to cancer treatment, it was deemed that all cancer related hospitals should have a symptom management clinic that would include lymphedema. At a minimum, the first step is to have each hospital at least acknowledge that lymphedema exists and that there are treatment options. Hospitals need to take a greater role in emphasis on prevention/education of lymphedema. Education needs to be imbedded in every cancer centre to provide patients with the tools to provide their own self-care.

Hospitals staff aren't properly trained or consistent in providing the post surgical care that protects the limbs at risk. For example, it is left up to the patient to advise the nurses to avoid taking blood pressure on the affected arm or inserting needles in the limb at risk.



Literature review

There is very limited published patient directed print material on lymphedema and the risk for cancer survivors in Ontario. There is an overwhelmingly number of books published that focus on breast cancer, however of the sample 50 books we scanned in retail bookstores, only 5% of them had more than a few lines (at most a chapter) dedicated to lymphedema.

Both the Canadian Cancer Society and Canadian Breast Cancer Foundation acknowledge lymphedema in their breast cancer literature. However, an important piece of information missing is the treatment options as well as the increased risk for infection in lymphedema patients and those at risk. On the other hand, the American Cancer Society – acknowledges the risk of lymphedema for many cancer treatments including breast/pelvis/prostate/melanoma/lymphoma and talks about treatment options such as Manual lymph drainage and compression therapy. They have recently produced a new book completely dedicated to lymphedema (American Cancer Society, Lymphedema Fall, 2006).

The reference material on lymphedema for health care professionals is even scarcer. The only clinical practice guidelines on lymphedema we found were two Canadian guidelines (dated 2000 and 2003), one international consensus document (dated 2003) and a more recent American position statement (2006) (see appendix).

The variance of information on lymphedema

The quality and comprehensiveness of hospital based patient education material we reviewed on lymphedema varies greatly from one cancer hospital to another. Some hospitals that diagnose and provide support to lymphedema patients have done extensive literature reviews and have produced comprehensive patient material on lymphedema. Some have an integrative education strategy on lymphedema, including information for the patients from the pre-operative to the post-operative stage. However there are other hospitals where badly photocopied handouts of outdated material are still being handed out to patients. A significant gap identified was the lack of standardized patient educational material on lymphedema. Although there is a variety of information available at various local levels, there isn't a single standardized source that seen to be most credible and authoritative, listing treatment options and available to all people living in Ontario. Of the four hospital patient libraries we sampled, only 1 had printed literature or books on lymphedema.



Emotional Aspects of Lymphedema

A frustrating element we heard from many patients with secondary lymphedema is their perception that the medical community doesn't recognize that the condition even exists as a problem. Even those that were made aware of lymphedema by their doctors, feel the implications were minimized – and most were told there is nothing that can be done about it. Yet the women we spoke to feel their lives, as they knew it were changed forever. We found our survey and focus group participants to be eager to share their lymphedema stories and grateful that finally someone was validating what they were going through.

In many aspects the challenge of lymphedema is worse for patients on an emotional level. Cancer has a beginning and an end, whereas lymphedema is chronic and can go on and on. Many patients told us that it was the compression garments themselves that contributed to their overall state of depression. Although they acknowledge that compression is an important component of recommended lymphedema treatment, garments are difficult to put on, uncomfortable to wear and very unsightly, especially in the summer months. The garments also attract a lot of undue attention and people constantly asking them what was wrong with their limb. For many, the out of pocket expenses for treatment therapy and garments was another constant challenge.

It was very difficult for many to grasp that although they felt reasonably content with the care they received for their cancer, they now felt they were left on their own to deal with some of the side effects such as lymphedema.

We did not find a lot of focus in addressing the emotional impact for lymphedema patients in Ontario. Although there are many breast cancer support groups that may cover lymphedema information, the only active support groups in Ontario with dedicated lymphedema focused sessions we were made aware of are Breast Cancer Action Kingston and Breast Cancer Action Ottawa as well as Lymphovenous Association of Ontario, in conjunction with Wellspring. The Consensus document from the International Society of Lymphology recognizes that psychosocial support with a quality of life assessment-improvement program is an integral component of any lymphedema treatment. We were also delighted to find a newly published book on *Overcoming the Emotional Challenges of Lymphedema* (see appendix).



RECOMMENDATIONS FOR FOCUSING PRIORITIES

Development of a comprehensive patient education strategy

- Ensure patient education about lymphedema is administered at the most opportune time; repeatedly (pre, during and post cancer treatment) and when learning about lymphedema is most relevant.
- Develop a lymphedema awareness pamphlet and poster for distribution at mammography clinics in Ontario. This would target the population with the highest risk of developing secondary lymphedema. It would also increase public awareness of lymphedema for every woman in Ontario over 50 years of age who goes regularly for breast cancer screening.
- Partner with breast cancer screening clinics in Ontario to help disseminate information about lymphedema
- Adapt best-in-class existing patient education materials promoting self-management of lymphedema to include practical guidance on accessing treatment options and how to navigate the Health system for reimbursement of appropriate compression garments. Distribute this standardized booklet to MLD therapists, garment fitters and participating lymphedema clinics.

Strengthen partnership with certified lymphedema therapists and partners in the breast cancer community

- Provide a forum for lymphedema specialized nurses and therapists across Ontario to share their knowledge, research and best practices in lymphedema treatment and patient education through networking opportunities and roundtable discussions.
- Assemble a repository and online library of existing best-in-class lymphedema literature for patients, community members and health care professionals to draw on. This could help reduce the amount of duplicate literature reviews and educational development happening simultaneously in various lymphedema centres around the province. There is good information about lymphedema already published, but isolated and not shared.

Reach out to the doctors and nurses that come into contact with lymphedema patients and those at risk

- Family physicians need to be made aware of what lymphedema is and how to access treatment options. Design and distribute a special kit for family physicians about lymphedema, including where to access clinical guidelines for treatment options
- Target doctors and nurses with lymphedema information through medical professional associations, conferences, hospital grand rounds etc.
- Enhance website to include more clinical information geared to professionals

Advocate for better patient care in the treatment of lymphedema

- Work with industry associations and lymphedema certification schools encouraging registered massage therapists, physiotherapists and occupational therapists to fill the need of more certified lymphedema therapists
- Support the need for symptom management clinics that include lymphedema within all the cancer hospitals



Next Steps

Of course, none of the above is possible without money and additional resources. The Lymphovenous Association of Ontario is not publicly funded and relies solely on donations and grants for the ongoing development of programs and services to support lymphedema patients and raise public awareness. That is why our first step is building relationships with other stakeholders in the lymphedema community and raising funding for these initiatives. It means we are busy writing various grant proposals, exploring other funding sources and initiating both private and corporate fundraising.

CONCLUSION

The LYMPH LISTENS project accomplished specific goals that had been set out:

- a deeper understanding of the physical, emotional and financial challenges facing breast cancer survivors that have lymphedema as their new legacy and to all breast cancer survivors at life-long risk for lymphedema, whether it is 3 months or 10 years after their initial cancer treatment.
- A strong knowledge base and repository of the current services, support and educational material that is available to breast cancer survivors, lymphedema patients and health care professionals working with lymphedema patients.
- A comprehensive report that documents our findings and the gaps between the community identified needs and the services and information currently provided.

It was inspiring to hear the stories of lymphedema patients in their quest to not only be treated for their condition, but to be heard and understood. They were willing to give us their perspectives on everything from coping with the condition to navigating the health care system. We also gained an understanding of how small the pool of lymphedema knowledgeable doctors, nurses and researchers is in Ontario. It was also valuable to gain a unique perspective on the challenges facing those that provide treatment and services to breast cancer survivors and lymphedema patients.

Armed with a more comprehensive understanding of the lymphedema community in Ontario, the Lymphovenous Association will be better equipped to chart our roadmap for the years ahead.



APPENDIX – Project Team Members

Name	Project Role	Project Responsibilities	Project-Related Skills & Experience
Anna Kennedy	Project Operations Project leader	Responsible for the project design and work plan. Accountable for managing project expectations, and leading the project team to accomplish project objectives within cost, timing and performance goals. Also responsible for continually tracking and analyzing project performance and communicating project status updates.	Over 25 years business experience in senior management roles and bringing leadership skills, project management, communication and training experience to the team. Brings relevant personal experience to the project since she is a cancer survivor herself living daily with lymphedema.
Anne Blair	Project Operations	Responsible for reviewing questions, participant selection criteria and identifying our target participants	A clinical oncology nurse for 26 years, specializing in breast cancer and lymphedema for the last 8 years. Has experience in facilitating support groups
Karen Banks	Project Operations coordinator	Responsible for interfacing with key contacts and reviewing services, support and material available to the various lymphedema stakeholders	Advance Care Paramedic and Past Vice President of LAO. Has many years experience establishing relationships and contacts within the Health Care community. Has first hand knowledge of lymphedema, having lived with it for 7 years
Ruby Kreindler	Project Operations Steering Committee	Responsible for ensuring that the emotional and psycho-social impact of breast cancer survivors and lymphedema patients was considered throughout all phases of the Needs Assessment Project	An experienced social worker who has worked on the development of various educational programs. Has facilitated formal support group sessions for breast cancer survivors and lymphedema patients in conjunction with Willow and Wellspring. Is herself a breast cancer survivor and lymphedema patient.
Judy Bedell	Advisory Role Health Care Representative	Provided specific knowledge, expertise and subject-matter consulting to the project team to ensure relevance and provide perspective on the specific audience represented	An active member of the Ottawa Breast Cancer Action group, involved in many projects supporting the BC and the Lymphedema community. Facilitator of lymphedema workshops and support groups.
Ian Dayes	Advisory Role Medical Community Representative	Provided specific knowledge, expertise and subject-matter consulting to the project team to ensure relevance and provide perspective on the specific audience represented	Radiation Oncologist treating patients with breast cancer. Fellowship training in Health Research methodology. Chair-Steering Committee of DELTA study, a CBCRA-funded randomized study comparing elastic sleeve and decongestive therapy in patients with lymphedema following treatments for breast cancer.



APPENDIX – Survey and focus group questions: Breast Cancer Survivors with lymphedema

- Tell us your age, gender and what city/town you live in
- What type of lymphedema do you have?
- Were you ever diagnosed and treated for cancer? If yes, what type of cancer did you have?
- At time of surgery, were you educated about lymphedema and risk reduction methods?
- Did you have radiation as part of your cancer treatment?
- How were you first diagnosed? (Family Doctor, Surgeon, Oncologist, other)
- When you were diagnosed with lymphedema, what information was given to you about the disorder/condition? By whom?
- How helpful/valuable was the information with which you were provided?
- Where else did you find information/support? (prompt: web, family doctor, hospital, lymphedema therapist, organizations)
- In your opinion, what has been the most valuable source of information?
- What treatments/therapies do you currently use to alleviate the symptoms? How frequent is your use of these treatments/therapies? Optimally, how frequently would you make use of these treatments/therapies?
- Optimally, what treatments/therapies/products do you think would help you best cope with the condition?
- How do you pay for your treatment/therapies/products?
- What are the barriers to accessing treatments for lymphedema?
- Do you know what treatment components are covered by OHIP or your own insurance?
- What community/charitable organizations are you aware of that provide support for people with lymphedema?
- What support do they provide/offer?
- What kinds of information and support services would be of greatest benefit in helping you cope with the condition?



APPENDIX – Survey and focus group questions: Breast Cancer survivors without Lymphedema

- What do you know about lymphedema?
- Before, during or after your treatment for breast cancer, were you informed about the risk of developing lymphedema?
- If yes, by whom? What information did you receive?
- How helpful/valuable was the information with which you were provided?
- If you developed lymphedema, where would you turn to for help?
- Do you know if products/treatments for lymphedema are covered by OHIP or your own insurance?
- Prior to participating in today's session, were you aware of any organizations exclusively dedicated to dealing with lymphedema?
- What kinds of information and support services would be of greatest benefit in helping you cope with the condition?



APPENDIX – Interview questions for Health Care and community representative stakeholders

FROM YOUR PERSPECTIVE:

- When a person is diagnosed with breast cancer, are they informed about the risk of developing lymphedema? If so, what information are they given?
- To your knowledge, approximately what percentage of people diagnosed with breast cancer are told about the risk of developing lymphedema?
- Can you tell us how much health care professionals such as breast cancer specialists, family physicians, and other health care providers know about the lymphedema?
- How would you describe the roles of hospitals; breast cancer specialists, lymphedema therapists, family physicians, and other health care providers in educating and managing lymphedema?
- How about the Ministry of Health's perspective: to what degree is lymphedema seen as a priority for funding?
- To your knowledge, to what degree are medical students taught about lymphedema as needed to diagnose the condition?
- What charitable/community organizations address the condition and what is their role in the care continuum?
- What are the barriers, if any, that people with the condition face in treating their condition more successfully?



APPENDIX – Representative Stakeholder interviews

Name	Credentials	Lymphedema community link
1. Dr. Ian Dayes	Radiation Oncologist	Juravinski Cancer Centre, Hamilton
2. Janet McFarland	Registered Physiotherapist, Certified lymphedema therapist and trainer	Toronto Lymphocare Centre
3. Anne Blair	Clinical Nurse, Breast Cancer and lymphedema clinic	Sunnybrook Hospital
4. Dena Shulman	Clinical Nurse and Certified Lymphedema Therapist	Scarborough General Lymphedema Clinic
5. Donna Lue Reise	RN and Certified Lymphedema Therapist	Private Practice
6. Diane Batchelor	RN and Lymphedema Therapist	Private Practice
7. Susan Bowles	Clinical Nurse, lymphedema clinic	Sunnybrook & Women’s Health Sciences
8. Sue De Vries	Clinical Nurse, lymphedema clinic	Toronto General Hospital
9. Marilyn Cecil Smith	Social Worker/Breast Cancer Support Group leader	London Regional Cancer Centre
10. Ysamine Ejbeck	Certified fitter for compression garments	The Medicine Shoppe
11. Cathy McPherson	President	Lymphovenous Canada
12. Susan Pilatze	Director	Thunder Bay Regional Cancer Centre
13. Kathy Germyn	Lymphedema Clinical Nurse	Sudbury Regional Cancer Centre
14. Sara Harrel	Lymphedema patient advocate	Successfully lobbied ADP for coverage of Reid sleeve
15. Mencie Laureta	Certified fitter for compression garments	Shoppers Home Health Care
16. Lyn Kligman	Clinical Nurse, Lymphedema Clinic	London Regional Cancer Centre
17. Kimberly Tweedie	RMT and Certified Lymphedema Therapist	Private Practice
18. Krys Moore	Lymphedema Clinical Nurse	Survivorship Program at Princess Margaret Hospital



APPENDIX – Lymphedema Community Organizations

Canadian

Name	Website	Their mandate
Alberta Lymphedema Learning Association	www.albertalymphedema.com	A learning association committed to ongoing education of its stakeholders, ALLA works to make a difference and empower affected individuals and their families to help manage this condition.
Lymphovenous Association of Ontario	www.lymphontario.org	Striving to improve the quality of life for people living with lymphedema by increasing public awareness, educating patients and health care professionals about both the risks and treatment of lymphedema and working to increase health care and insurance coverage for treatment and care for lymphedema patients
Lymphovenous Association of Quebec	www.infolympho.org	Providing education, awareness, and support to those with lymphedema, and to encourage research leading to effective treatments and eventually a cure.
Lymphovenous Canada	www.lymphovenous-canada.ca	An e- based information to link people with Lymphovenous disorders to research news, events and education materials.

US based

National Lymphedema Network	www.lymphnet.org	Provides education and guidance to lymphedema patients, health care professionals and the general public by disseminating information on the prevention and management of primary and secondary lymphedema.
Lymphedema Awareness Foundation Lymph Notes	www.laf www.lymphnotes.com	Promotes lymphedema awareness by establishing referral networks and outreach programs for health care professionals and lymphedema patients. Provide awareness tools and educational materials.
Lymphedema Circle of Hope	www.lymphedemacircleofhope.org	An organization dedicated to promoting education, awareness, research, assistance, and support to lymphedema patients and their doctors.
Lymphedema People	www.lymphedemapeople.com	An information portal created for, and by, people with the medical condition Lymphedema.

International

United Kingdom	www.lymphoedema.org.uk	Educates and supports lymphedema patients by providing a high standard of information and promoting self help.
Australia	www.lymphoedema.org.au	Encourages research into lymphedema and its treatment and spreads information about these to doctors, therapists and patients.



APPENDIX – Lymphedema Books

Geared to patients

Title	Author	Date and Publisher
Coping with Lymphedema	Joan Swirsky	2002 Avery
Lymphedema – A breast cancer patient’s guide to prevention and healing	Jeannie Burt and Gwen White	1999 Hunter House
Living Well with Lymphedema	Ann Ehrlich, Alma Vinje-Harrewijn, Elizabeth McMahan	2005 Lymph Notes
Overcoming the Emotional Aspects of Lymphedema	Elizabeth McMahan	2005 Lymph Notes
Lymphedema – Treatment and Diagnosis	American Cancer Society	2006 American Cancer Society

Geared to health care professionals

The Diagnosis and Treatment of Peripheral Lymphedema	Executive Committee, International Society of Lymphology:	1995; 28 113-117.
Lymphedema An Information Book for Patients, Their Medical Practitioners and Health Care Workers	Judith R. Casely-Smith and J.R. Casely-Smith.	Tenth edition, January 2003
Comprehensive Lymphedema Management	Joachim Zuther	2004 Thieme Medical Publishers
Lymphedema Diagnosis and Therapy	H. Weissleder and C. Schuchardt	Third Edition, 2001
Textbook of Lymphology	M. Foeldi and E. Foeldi	2003 Klose Training and Consulting



APPENDIX – Lymphedema Clinical Guidelines

<i>Clinical practice guidelines for the care and treatment of breast cancer:</i> 11. Lymphedema by Susan R. Harris, Maria R. Hugi, Ivo A. Olivotto, Mark Levine and the Steering Committee for Clinical Practice Guidelines for the Care and Treatment of Breast Cancer (2000)	www.cmzj.ca/cgi/content/full/164/2/191
<i>The Treatment of Lymphedema Related to Breast Cancer Evidence Summary Report #13-1</i> by Kligman L, Wong R, Johnston M, Laetsch N, and members of the Supportive Care Guidelines Group and sponsored by Cancer Care Ontario (2003)	www.cancercare.on.ca/pdf/pebces13.1s.pdf
<i>National Lymphedema Network (USA) New Treatment Guidelines</i> (2006)	www.lymphnet.org/pdfDocs/nlntreatment.pdf
<i>ISL Consensus Document on the Diagnosis and Treatment of Peripheral Lymphedema</i> (2003) by International Society of Lymphology	www.u.arizona.edu/~witte/2003consensus.pdf



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Author:
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Summer 2006

416-410-2250 or 1-877-723-0033

www.lymphontario.org



With thanks to the Canadian Breast Cancer Foundation – Ontario Chapter

