The Canadian Lymphedema Framework: Improving Lymphedema education, research and management
Comprehensive effective treatment for lymphedema and related disorders will be accessible to all persons across Canada
The lymphedema problem in Canada and worldwide: where are we at?
Activities of the Canadian Lymphedema Framework
Standards of care
Educational and Research priorities
Models of lymphedema care for the future
Lack of awareness, lack of research, insufficient education, nonexistent or inadequate clinical programmes...
Reoccurrence rate at 26% per year for persons with arm lymphedema with at least one episode of erysipelas (Vignes).

A study in France to assesses risk factors for hospital admission for cellulitis gave the highest odds ratio for lymphedema=71.2X (Dupuy)
OBESITY

- Obesity: BMI 30-39.0
- Morbid Obesity: BMI 40 or higher
OBESITY RATES

- Obesity is the fastest growing chronic condition in North America
- Almost one-third of intensive care unit patients are obese
OBESITY AND LYMPHEDEMA

- Under-recognized link between obesity and lymphedema
- Bariatric treatments
- Unrecognized value of conservative treatments for lymphedema related to obesity, in favour of surgical debulking
- Public health issue
THE OBESITY PROBLEM IN CANADA

Percentage who were underweight, normal weight, overweight and obese (self-reported), by age group, household population 18 or older, Canada Public Health survey, 2010
On the basis of measured height and weight from multiple sources during 2007-2009, more than one in four adults in Canada are obese.
% OF POPULATION OVER 20% OF IDEAL BODY WEIGHT

Overweight and obese, G-7 countries, 2004 and 2005 (percent)

- Japan (2004): 23%
- France (2004): 35%
- Italy (2005): 45%
- Germany (2005): 50%
- Canada (2005): 50%
- United Kingdom (2005): 60%
- United States (2004): 66%
For Canada...

Overweight and obese, by gender, 2005 (percent)

- Overweight:
  - Men: 41%
  - Women: 29%

- Obese:
  - Men: 26%
  - Women: 23%
FOR CANADA...

Overweight and obese, by age, 2005
(percent)

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Overweight</th>
<th>Obese</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-34 years</td>
<td>27%</td>
<td>13%</td>
</tr>
<tr>
<td>35-54 years</td>
<td>35%</td>
<td>27%</td>
</tr>
<tr>
<td>55-64 years</td>
<td>44%</td>
<td>33%</td>
</tr>
<tr>
<td>65-74 years</td>
<td>39%</td>
<td>34%</td>
</tr>
<tr>
<td>75+ years</td>
<td>42%</td>
<td>22%</td>
</tr>
</tbody>
</table>

Legend:
- 18-34 years
- 35-54 years
- 55-64 years
- 65-74 years
- 75+ years
## OBESITY IN CANADA 1978-2005
### (Prevalence - Measured Values)

<table>
<thead>
<tr>
<th>Canada, 1978-2005 (18 or older)</th>
<th>1978</th>
<th>2004</th>
<th>2005</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total overweight and obese (BMI ≥ 25)</td>
<td>49</td>
<td>59</td>
<td>59</td>
</tr>
<tr>
<td>Overweight (not obese) (BMI = 25 to 29.99)</td>
<td>35</td>
<td>36</td>
<td>35</td>
</tr>
<tr>
<td>Obese (BMI ≥ 30)</td>
<td>14</td>
<td>23</td>
<td>24</td>
</tr>
<tr>
<td>Obese Class I (BMI = 30 to 34.9)</td>
<td>10.5</td>
<td>15</td>
<td>17</td>
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<tr>
<td>Obese Class II (BMI = 35 to 39.9)</td>
<td>2.3</td>
<td>5.1</td>
<td>4.8</td>
</tr>
<tr>
<td>Obese Class III (severe) (BMI ≥ 40)</td>
<td>0.9</td>
<td>2.7</td>
<td>2.1</td>
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</table>
OBESITY RATES IN CANADA
Obesity trends among U.S. Adults between 1985 and 2010
During the past 20 years, there has been a dramatic increase in obesity in the United States.

In 2010, no state had a prevalence of obesity less than 20%. 12 states had a prevalence of 30% or more.
Leannest State: Colorado 19.1%
Fattest State: Mississippi 33.8%

Percentage of Obese Adult Population
(3-year average from 2007-09 CDC Behavioral Risk Factor Surveillance System data)
In 1990, 10 states had a prevalence of obesity less than 10% and no state had prevalence equal to or greater than 15%.
Obesity Trends* Among U.S. Adults
BRFSS, 1990, 2000, 2010

(*BMI ≥30, or about 30 lbs. overweight for 5’4” person)
The Canadian Physical Activity Levels Among Youth (CAN PLAY) study estimated that during the 2007-2009 period, 88% of children and youth aged 5 to 19 did not meet the guidelines of Canada’s Physical Activity Guide.
In the 2007/08 CCHS survey, only half (51%) of Canadians aged 12 and over were active or moderately active.
RECOGNIZED STRONG ASSOCIATIONS WITH OBESITY ESPECIALLY WITH INCREASED VISCERAL FAT

- Diabetes
- Cardiovascular disease
- Hypertension
- Cerebrovascular accident (stroke)
- Pulmonary dysfunction
- Gallbladder disorders
- Multiple organic dysfunction syndrome (MODS)
- Cancer and cancer recurrence (breast)
- Arthritis, gout
A crude estimate of approximately 15000 patients attending a US clinic showed almost 75% of morbidly obese patients have chronic oedema of the legs (Todd, 2009)
OBESITY-RELATED LYMPHEDEMA

.... and the lymphedema is mostly unrecognized and untreated
COMPLICATIONS OF OBESITY-RELATED LYMPHEDEMA

- Cellulitis
- Life-threatening septicemia
- Chronic wounds that do not heal
- Immobility
- Disability and job loss
Little research has been done to study the link between obesity and lymphedema, and the impact of lymphedema on skin integrity and wound healing.
Comprehensive effective treatment for lymphedema and related disorders will be accessible to all persons across Canada.

Improving lymphedema care: the power of international collaboration.
INTERNATIONAL LYMPHEDEMA FRAMEWORK

Prof Christine Moffatt
University of Glasgow
Eight standards of practice for people with lymphedema: a framework for the ILF and its partner organisations to work towards.
STANDARDS OF PRACTICE FOR LYMPHEDEMA

- **Standard 1**: Awareness and knowledge of lymphedema within the community
- **Standard 2**: Identification of people at risk of or with lymphedema
- **Standard 3**: Empowerment of people at risk of or with lymphedema
- **Standard 4**: Provision of lymphedema services that deliver high quality clinical care that is subject to continuous improvement
- **Standard 5:** Access to appropriately trained health care professionals
- **Standard 6:** Provision of high quality clinical care for people with cellulitis
- **Standard 7:** Provision of optimal, individualised programmes of care
- **Standard 8:** Provision of multi-disciplinary health and social care
American Lymphedema Framework Project
Dr Jane Armer, University of Missouri
Founded in 2008

Canadian Lymphedema Framework
Dr Anna Towers, Dr. David Keast
Founded in 2009
Comprehensive effective treatment for lymphedema and related disorders will be accessible to all persons across Canada.
Executive Committee Members
Dr. Anna Towers: Co-Chair
Dr. David Keast: Co-Chair
Anna Kennedy, Rachel Pritzker and Christine Moffatt

Administrative support: Jill Allen, Pamela Hodgson
A registered charity, the CLF is an academic and patient stakeholder collaboration - part of an international initiative that aims to promote research, best practices and lymphedema clinical development, worldwide.
Theme of stakeholder meeting
Nov 2009:
What can we do to improve the management of lymphovenous disorders in Canada?
110 lymphedema stakeholders attended with almost equal participation from:

<table>
<thead>
<tr>
<th>Stakeholder Group</th>
<th>Stakeholder Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>therapists</td>
<td>physicians</td>
</tr>
<tr>
<td>patients</td>
<td>nurses</td>
</tr>
<tr>
<td>industry representatives</td>
<td>funders</td>
</tr>
<tr>
<td>government representatives</td>
<td></td>
</tr>
</tbody>
</table>
“A vicious circle of lacks.”
KEY DEVELOPMENT AREAS IDENTIFIED

+ Research
+ Advocacy
+ Reimbursement and policy issues
+ Education
+ Standards of care
THE LYMPHEDEMA WEB OF AWARENESS

- Medical & Health Care
- Patient
- Public
- Education
  - Standards
  - Research
  - Reimbursement & Access
  - Policy

Awareness
WORKING GROUPS

1. Education
2. Research
3. Partnership building and fundraising
Prevalence of lymphedema: “We need to survey the landscape”

Resource list for existing Canadian research

Encourage clinical trials on the effectiveness of lymphedema therapy

Risk reduction and prevention
Improving education for lymphedema therapists, and all health care practitioners
MULTI-DISCIPLINARY EDUCATIONAL INITIATIVES

- Lymphedema therapists
- Physicians
- Physiotherapists
- Nurses
- Occupational therapists
- Massage therapists
EDUCATION

Curriculum Development:
Undergraduate
Postgraduate
Continuing education
Education Working Group
Nadine Maraj-Niri, Martina Reddick (Co-Chairs)
Linda (Koby) Blanchfield, Michael Eid, Adriana Golob, Robert Harris, Pamela Hodgson, Michelle Horst, Pamela Hilliard, Leslie Hutchings, Jan McFarland, Edith Mulhall, John Mulligan, Casi Shay, Dorit Tidhar, Anna Towers, Janice Yurick
Educational activities

Training standards
- Collated curriculum Information from the major (private) lymphedema schools in Canada

Consistency in presentations to health professionals
- Organised a resource library of 355 slides

Under-graduate health sciences curricula
- Survey/questionnaire distributed to 100 university and college programs across Canada
Research

• Collected information on lymphedema studies in Canada and developed a comprehensive list of Canadian researchers working in the field

• Created an extended Research Advisory Network to assist development of funded research projects

• Planning a prevalence study, CIHR
Research Working Group
Bev Lanning, Roanne Thomas-MacLean (Co-Chairs)
Sylvia Crowhurst, Pamela Hodgson, Miles Johnston, Winkle Kwan, Margie McNeely, Cathy McPherson, Deborah Ruskin, John Semple, Andrea Tilley, Anna Towers
Partnership Development and Fundraising

Bonnie Baker (Chair)
Kim Avanthay, David Keast, Anna Kennedy, Claire Ann Deighton-Lamy, Rachel Pritzker, Linda Venus
The CLF is modelled on, and has a partnership agreement with, the International Lymphoedema Framework, and through it links with other national frameworks.
CLF STRUCTURE

Executive Committee
Anna Towers: Co-Director
David Keast: Co-Director
Rachel Pritzker
Anna Kennedy
Christine Moffatt

Adminstration Support
Pamela Hodgson
Jill Allen

Advisory Board
Robert Harris  Cathy McPherson
Jan McFarland  Linda Venus
Kim Avanthay  Janice Yurick
Martina Reddick  Roanne Thomas-MacLean

Research Working Group
Education Working Group
Partnership Development Working Group
## ADVISORY BOARD MEMBERS

<table>
<thead>
<tr>
<th>Name</th>
<th>Location</th>
<th>Role and Responsibilities</th>
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</thead>
<tbody>
<tr>
<td>Roanne Thomas MacLean</td>
<td>Saskatoon, Saskatchewan</td>
<td>Researcher specializing in the impact of psycho-social issues of lymphedema in breast cancer patients</td>
</tr>
<tr>
<td>Robert Harris</td>
<td>Victoria, British Columbia</td>
<td>Director of Vodder School International – teaching certification classes to therapists</td>
</tr>
<tr>
<td>Jan McFarland</td>
<td>Cookstown, Ontario</td>
<td>Co-Director of Toronto Lymphocare. Provides treatment for patients as well as teaches classes to therapists</td>
</tr>
<tr>
<td>Kim Avanthay</td>
<td>Lac du Bonnet, Manitoba</td>
<td>Lymphedema advocate and mother of a young son with lymphedema</td>
</tr>
<tr>
<td>Martina Reddick</td>
<td>St. John’s, Newfoundland</td>
<td>Lymphedema nurse practitioner, Cancer Care Program at East Health Region</td>
</tr>
<tr>
<td>Cathy McPherson</td>
<td>Toronto, Ontario</td>
<td>Patient with primary lymphedema and Website manager/administrator of <a href="http://www.Lymphovenous%E2%80%93Canada.org">www.Lymphovenous–Canada.org</a></td>
</tr>
<tr>
<td>Linda Venus</td>
<td>Winnipeg, Manitoba</td>
<td>Lymphedema patient, Senior Director at Canada Cancer Society, Manitoba Division</td>
</tr>
<tr>
<td>Janice Yurick</td>
<td>Edmonton, Alberta</td>
<td>Physiotherapist with the lymphedema program at Cross Cancer Institute in Edmonton</td>
</tr>
<tr>
<td>Casi Shay</td>
<td>Montreal, Canada</td>
<td>Physiotherapist, McGill Lymphedema Program</td>
</tr>
</tbody>
</table>
Other CLF Projects and Activities

- Co-hosted the 3rd ILF Conference

- Contributing to Canadian lymphedema education
  - Peer-reviewed journals and other publications
  - Invited presentations

- Contributing to global health education
  - Ugandan hospital site visits
KEY MILESTONES TO DATE

- February 5-6, 2009: CLF Founders meeting
- November 6, 2009: National Stakeholder Meeting, Toronto
- February 2010: Palliative Care Best Practices
- June 2010: national charitable status approval
- March – June: 2010 Therapist survey
- June 16-18 2011 – hosted ILF Conference, Toronto
- PATHWAYS magazine- April 2012
INTERNATIONAL LYMPHOEDEMA FRAMEWORK

3rd INTERNATIONAL CONFERENCE

In collaboration with the
CANADIAN LYMPHEDEMA FRAMEWORK

TORONTO JUNE 16-18, 2011

www.lympho.org/3rd-ilf-conference.php
Update of Best Practice Guidelines Based on systematic reviews
MEASUREMENT METHODS USED TO ASSESS LYMPHEDEMA

Source: Q20
Base: All respondents (N=239)
HOW DO WE PROMOTE THE USE OF BEST PRACTICE?

- Advocate for Best Practice being a core for basic and continuing education for lymphedema and other health care professionals
- Advocate to have lymphedema indicators as part of accreditation standards for departments and institutions (e.g. cancer centres, wound clinics)
Assessing the Lymphedema Landscape

Phase 1 - Online Survey
LYMPHEDEMA LANDSCAPE

Canadian Survey - 2010

A collaborative project with 3M
PURPOSE - TO DOCUMENT

- level of lymphedema training and certification of health professionals who assess/treat patients with lymphedema
- types of lymphedema seen
- the profile of care settings
- treatments and services provided
Massage therapists (113)  
Physiotherapists (69)  
Nurses (30)  
Other
WHETHER HAVE TRAINING IN CDT FROM A QUALIFIED SCHOOL

- No: 32%
- Yes: 68%

Source: Q12/13
Base: All respondents (N=239)

- RMT: 87%
- Physio: 67%
- RN/NP/RPN: 47%
PRACTICE SETTING

- Private practice: 45%
- Hospital: 14%
- Home care: 8%
- Palliative/long-term care: 11%
- Other: 22%
INTENSIVE PHASE
FREQUENCY OF PATIENT VISITS

- 4-5 x/wk: 30%
- 2-3 x/wk: 27%
- 1 x/wk: 27%
- every 2 wks: 13%
- Less than every 2 wks: 3%
COMPONENTS OF CARE

- Exercise education
- Risk reduction education
- Self bandage education
- Self drainage education
- Kinesiotaping
- Full CDT
- MLD
- Compression bandaging
MEASUREMENT TOOLS

- Circumferential measure & Skin Pain/function/ROM/mobility
- Photographs
- Vascular
- BMI/Pyschological
- Do NOT Assess

0 22.5 45 67.5 90
CLINICAL GUIDELINES FOLLOWED

ILF Best Practice
Dr Vodder School
Am Cancer Society
NLN/LANA/other
None

0 12.5 25 37.5 50
KEY LEARNINGs

- Post-graduate training needed among health professionals managing lymphedema
- Use of clinical guidelines and assessment tools need fuller integration into lymphedema care
INTERDISCIPLINARY MODELS OF CARE

Cancer Treatment Centre
- Post-treatment education and rehabilitation

Medical and Surgical Units
- Specialized lymphedema and wound care services

Community services
THE CHRONIC CARE MODEL

REF Best Practices for Lymphedema
version 2, 2012
The chronic care model is a pragmatic approach based on the following assumptions:

- That the patient is the center of the care process
- That all professionals integrate into the model and cooperate closely together
- That the patient has an active role (care manager) rather than being a passive ‘care consumer’. Aspects such as self management and self efficacy are very important
- That healthcare workers do not merely focus on symptom control (for example, reduction of swelling), but act as ‘coaches’ with ‘hands-off’ approach
The chronic care model is based on the following assumptions (2):

- That the model and integrated approach is based on guidelines, evidence based medicine and best practice documents, to which all health professionals are committed
- That standardized and validated measuring methods and questionnaires will be used to monitor the effects of treatment programs
- That effective, digital electronic patients files and mutual communication between healthcare workers and patients will be ensured
The role of self-management

The CCM allows self-management as a core component. Self-management is the ability of an individual to cope with symptoms, treatment, physical and social consequences and lifestyle changes related to a life living with a chronic disease\textsuperscript{15}. To achieve this goal, four domains are offered (box 1):
SELF MANAGEMENT DOMAINS
(REF BDP 2-2012)

- Activities focused on health improvement and build up of physical resistance
- Coping with healthcare providers and compliance to treatment
Comprehensive effective treatment for lymphedema and related disorders will be accessible to all persons across Canada.

“THERE IS MUCH THAN CAN AND SHOULD BE DONE.”

DR JUDITH CASLEY-SMITH
informed and activated patient prepared, proactive team