

National Lymphedema Conference Report, Calgary AB. October 23-24, 2015

This report covers the sessions that I attended.

Provincial Association Networking Session

This session was attended by representatives from British Columbia, Alberta, Saskatchewan Manitoba, Ontario and Quebec, along with Anna Kennedy and Dr. David Keast from the Canadian Lymphedema Framework (NLF).

Each representative said a little about their organization, its strengths and struggles. All other provinces are envious of the coverage Saskatchewan has, thanks to the Working Group, and also that we are continuing conversations with the government.

Manitoba has a necklace and pin that they sell. On March 4th they will be hosting a "Pin Campaign" across the province. They were pleased that the Health Minister attended their conference

British Columbia is down in members, and is struggling for registration for their conference. They are contacting local papers and media to get the message out. The Sun has shown real interest. At their conference, they will be taping patients' stories and will take this tape to the Minister of Health. BC has an information line answered by a person and sends out info as requested.

Quebec feels each Association has different needs (Bilingual) and they are they are financially starving. They would like to see just a national organization.

Ontario is struggling to stay alive.

The Canadian Lymphedema Framework outlined their responsibilities and those of the provincial organizations. CLF is mainly education, research and partnerships and the provinces look after their own local needs. CLF will host a national conference every second year, co-hosting with a province.

CLF's main discussion was about Pathways. The costs are rising and will go up in the future. Right now we are charged \$1.50 per magazine plus cost of the insert. The cost to provinces might go to a scale cost, the more ordered, the cheaper per magazine. They will print brochures every 6 months; cost again varies, depending on the quantity ordered.

Opening Preliminary Session included a welcome address by Dr. Keast, Anna Kennedy (CLF) and Dianne Martin (ALA)

Guest Speaker 1 - Dr, John MacDonald "Lymphedema, An International Perspective"

Dr. MacDonald spoke about his work in Haiti, mostly with wound care. I will be brief with this report as we have a write-up on the same topic in the Winter 2016 LAS insert. The greatest concern is Lymphatic Filariasis caused by insects. Approximately 88 percent of the population is at risk, with the mean age being 21. However there are fewer than 2000 hospital beds available. Much funding and volunteers are needed.

Guest Speaker 2- Dr. C. Moffatt “How Big is the Lymphedema Problem? LIMPRINT”

Dr. Moffatt is from the University of Nottingham, United Kingdom. She is very involved in research, especially LIMPRINT-an international multi-site population based study to determine the prevalence and functional impact of lymphoedema /chronic oedema in the adult population of member countries of International Lymphedema Framework.

In the United Kingdom in 2003, 823 patients out of 619,000 people had lymphoedema and the numbers increased with age. 60% of these patients had non-cancerous lymphoedema. 80% of the patients had taken time off from work and 8% had to stop work. In 2013, the numbers were 3 times more than in 2003 with primary lymphedema being 17% and secondary lymphedema being 82%, but only 31% of that number is cancer-related. Obesity is a major contributor, the more fat, and the more chance of cellulitis. This is not a rare problem that is going to go away.

“ALA Advocacy to AHS Action: to Lymphedema Services” Presenters Lisa Warner and Dianne Martin

On January 20th, 2014, Alberta became the first province to gain public funded treatment coverage for all patients with the opening of the Calgary Ambulatory Lymphedema Service (CALs). It is open 4 days a week to service patients 16 years of older and sees 20 patients a week.

Edmonton already had a clinic and Calgary was determined to also have one. They advocated to ensure that Albertans with lymphedema were getting care and also to educate the medical personnel that care for them. Some steps taken included a letter writing campaign, meeting with several health ministers and initiated a lymphedema working group to include the Alberta Lymphedema Association as a partner. This resulted in a design and implementation of the Lymphedema Clinic, CALs Clinic.

They emphasised that you need to take every opportunity to advocate by distributing education printed material to hospitals and doctors, speaking at conferences, using the social media, letter writing and meeting with the health minister and member of parliament of Health Services director.

They also have a clinic in Red Deer and Lethbridge for secondary cancer-related cancer lymphedema patients, but only in Calgary and Edmonton for primary and non cancer lymphedema patients. In Calgary there is a 4-6 week waiting list for cancer related Lymphedema patients and a 26 month waiting list for non-cancerous lymphedema. They expected to have about 100 on the waiting list, but now have 250 on the waiting list.

CDT is the method of treatment at these clinics which includes manual lymph drainage, compressions, skin care, exercise and education for self management. When all seems to be going well, they receive a once a year check and are provided with a list of private therapists.

“Self Managing Lymphedema –Take Control” presented by Lori Radke and Elizabeth Giriling

Lori began the presentation with this comment “Self management and self care take a lot of care and is hard work and aging complicates self care” .They then presented the Top Ten Self Care Tips which were in the Summer Edition 2015 Pathways so I will be very brief.

The ten tips include:

10. **Risk Reduction** -Try to avoid any triggers including a healthy weight and infection.
9. **Soft and Smooth**-The key goal is to prevent cellulitis in the affected limb or body. They suggest an application of a good moisturizer with a low ph at least twice a day to reduce the risk of skin break down and subsequent infection.
8. **Compression** – Compression can produce a 17% to60 % reduction. It is important to teach people how to self bandage, including night bandaging which is often very important, especially when you are trying to maintain the volume reductions achieved from intensive CDT treatment. Day compressions garments should not be worn at night. Another option to replace layer compression bandaging is the lighter 2 layer coban bandaging system.
7. **All Compressions Garments are Not Created Equal.** Two options for compression are ready made garments and custom made garments. It is very important to have a good fitter. Garments should be replaced every 4-6 months as volumes increase with older garments.
6. **Lymphedema and Exercise**-They can and should go together. You should get medical clearance from your doctor before starting any exercise program, always start at low weights and repetitions and wear your garments during exercise. There may be other precautions for lower extremities.
5. **It Takes a Village to Manage Lymphedema** – This team may consist of the some or all of the following people: your family physician, a certified lymphedema therapist who has gone through a minimum of 135 hours of training, a knowledgeable and caring garment fitter, home care, a wound care clinic, a nutritionist, a psychosocial services, a fitness trainer who is knowledgeable about lymphedema and of course your family and friends.
4. **Consider Self Care-as Me Time**- Rather than resent the time it takes to look after yourself, consider it “me: time.
3. **Check in Regularly with Your Lymphedema Therapist**-This should be at least once a year to see if everything is on the right track and to be inspired to keep up with the self-care.
2. **There is No Single Recipe for Treatment.** YOU and your therapist must figure out what treatments work best for you, and devise a customized lymphedema management plan. However we know that early treatment is better than late treatment and brings better results.
1. **Learn from Others**- Many patients shared their tips on what best worked for them.

“EXERCISE-Debunking the Myths” presented by Dr. Kristan Campbell BSC. PT PHD from the University of British Columbia

The thoughts around exercise and lymphedema has changed a lot, starting in 1996 with the “Abreast in a Boat”, the Dragon Boat Race. Susan Harris studied the participants of this event and saw no significant change in the paddlers before or after the event, but they showed a marked improvement in both physical and mental health.

She reported on several other studies, but these studies were all breast cancer related lymphedema. These studies indicated that individuals with secondary lymphedema can safely participate in progressive, regular exercise without experiencing a worsening of lymphedema and/or symptoms. There also appears to be no evidence as to whether a sleeve should be worn or not be worn for exercise.

More research is needed on lower extremity lymphedema and how exercise affects it.

Submitted by Verna Schneider