

# Reimbursement inequities

## Provincial discrepancies for lymphedema care

The financial burden and barriers for patients...its just not fair

By Anna Kennedy and Nicole Boulet

Lymphedema is a chronic, progressive condition characterized by the accumulation of lymph fluid (swelling) due to a malfunction in the lymphatic system. It is now estimated that more than 700,000<sup>1</sup> Canadians are living with lymphedema.

For people who develop other chronic conditions such as diabetes or coronary heart disease, there are education and rehabilitation programs in place to help them return to healthy, productive lives. Unfortunately similar programs are not readily available for all Canadians living with lymphedema. The reality is that where you live and how you developed lymphedema dictates the extent to which the lymphedema treatment you receive is covered under universal health care or must be paid out of pocket.



### Treatment

Treatment for lymphedema is known as Combined Decongestive Therapy (CDT) or Decongestive Lymphatic Therapy (DLT) and consists of various kinds of compression, skin care, exercise and special massage techniques to reduce swelling and maintain the size of the afflicted body part. The initial phase of treatment demands an intensive

therapy regimen comprising of skin care, bandaging, exercise, elevation, and manual lymphatic drainage (MLD)<sup>2</sup>. Once the swelling has been brought under control, long-term management of lymphedema involves exercise and daily wearing of compression garments to control symptoms and enhance the function of lymphatic vessels<sup>3</sup>.

Compression is the single most important component in treating patients with lymphedema. Chronic lymphedema requires continuous compression<sup>3</sup> as the maintenance of the lymph fluid reduction is directly related to adherence to night and daytime compression. Supplies required to support compression for lymphedema include: standard fit and customized gradient compression garments, multi-layer compression bandaging systems, compression wraps and other compression supplies and devices.<sup>2</sup>

### Compression costs

The cost of compression varies greatly depending on the severity of the lymphedema, the body part involved (arm vs. leg), the type of garment prescribed, and whether custom or standard fit is required. Breast cancer patients often require standard fit or a lower grade compression garment, whereas patients with lower leg lymphedema typically require stronger

compression, flat-knit and custom ordered garments. A person living with lymphedema can spend as much as \$4000 per year on compression garments and bandaging alone.

### Adherence to treatment

As there is currently no cure for lymphedema, adherence to a self-management routine is essential for patients to maintain reduction of their symptoms in the long term<sup>3</sup>. Increasingly, both hospital based and private clinics follow a chronic care self-management model where health care professionals act as coaches to patients (a “hands-off” approach) and encourage individuals to use compression on a daily basis and to exercise regularly.

### Barriers to treatment

Adherence to treatment requires significant commitments of time, energy and financial resources from the patient. Research has found suboptimal levels of adherence to self-management among women with breast cancer related lymphedema. Therapists in one study agreed that adherence was negatively impacted by several potential barriers, including access to treatment and financial cost<sup>3</sup>. Several studies have also described distress related to financial burdens and insufficient health coverage as contributing factors to the psychosocial aspect of living with lymphedema<sup>6</sup>. Canadians with lymphedema indicated that cost is the most significant barrier to accessing treatments that are needed to cope with their condition<sup>9</sup>.

The financial impact of the burden of adhering to lymphedema treatment is significant to patients and to society as a whole. When patients avoid treatment in order to save money, higher rates of hospitalization due to serious complications such as cellulitis can occur, resulting in significant costs to the provincial health care system<sup>7</sup>.



**Anna Kennedy** is the Editor of *Pathways*, Executive Director and founding member of the Canadian Lymphedema Framework. She was also appointed to the International Lymphoedema Framework board of directors since 2011.



**Nicole Boulet** works part-time as the *Pathways* Editorial Intern for the Canadian Lymphedema Framework. She is currently in the Masters Communications Studies program at Wilfrid Laurier University in Waterloo, Ontario.

## Inequitable access to treatment

The Canadian Lymphedema Framework, in collaboration with provincial lymphedema associations published a 2016

Reimbursement Report outlining the varied coverage by provincial health care programs for lymphedema treatment.

The report highlights the inequity in reimbursement showing that while a few provincial health care programs provide some reimbursement, other provinces provide none at all. In many provinces, the cost of care is only covered if patients are fortunate enough to access the few specific treatment centres within a hospital setting.

## Why the disparity in funding?

The Canadian health care system is good at delivering acute care and essential services to its citizens, e.g., hospitalization and surgeries due to a life-threatening illness or event, such as cancer. It is the components of health care deemed to fall outside of essential services that creates the inequity. Importantly, the position of lymphedema management within the health system is not clear<sup>8</sup>.

Canada's federal health care act dictates what funding the provinces will receive for health care. The provincial ministries decide where to allocate these funds, usually to local regional health networks. This

“The Canadian Lymphedema Framework’s goal is to address issues of inequality of provision. We have a responsibility to care for those with lymphedema in ALL settings and for lymphedema of any etiology.”

–Dr. Anna Towers, Lymphedema Program Clinical Director, McGill University Health Centre (MUHC), Quebec.

allocation system results in huge disparities for Canadians living with lymphedema.

Unfortunately where you live is not the only determinant of the level of reimbursement for lymphedema. Some provinces dictate how much reimbursement you are eligible for, depending on whether you have primary lymphedema, secondary lymphedema, breast cancer-related or non-breast cancer-related lymphedema. Imagine if the extent to which a patient with diabetes or parkinson's disease received care was determined by how they acquired the disease or the type.

## Conclusion

Of all the components of CDT, the effectiveness of compression has the most supporting evidence and as such is the most commonly prescribed treatment.

Despite this, many people with lymphedema in Canada are not eligible for funding to cover the expensive compression devices that are compulsory to manage their condition. Those who are particularly

disadvantaged are people without access to private insurance through an employment plan and who cannot afford extended health insurance.

## Get involved

The health care programs in all Canadian provinces and territories should provide lymphedema patients with access to consistent, affordable treatment. The provincial lymphedema associations are actively engaging their provincial governments to make this happen. We encourage patients, therapists and clinicians to join their local association and lend their voice and talents to this important advocacy work. [LP](#)

A full set of references can be found online at [www.lymphedemapathways.ca](http://www.lymphedemapathways.ca).

### Editor's Note:

A full copy of the CLF 2016 Lymphedema Reimbursement report can be found at [www.canadalymph.ca](http://www.canadalymph.ca).



## REGIONAL COMPARISON - REIMBURSEMENT OF COMPRESSION SUPPLIES

Some provinces provide partial funding for compression supplies under Assistive Devices Programs while other provinces have no particular programs in place.

- 1) Saskatchewan:** 4 compression garments provided annually (100% reimbursement) plus 1 nighttime garment (every 2 years), bandaging systems and accessories, partial funding for pneumatic pumps (primary lymphedema patients only)
- 2) Ontario:** 6 compression garments per year (75% reimbursement) plus nighttime garments, pneumatic pumps (primary lymphedema patients only)
- 3) Alberta:** 3 standard fit or 2 custom fit compression garments per year (75% reimbursement of benchmark price)
- 4) Quebec:** 1 daytime or nighttime compression garment per year plus one set of multi-layer bandaging (both at 75% reimbursement)
- 5) British Columbia:** 2 compression sleeves/gauntlets per year (\$150 max-standard fit or \$300 max-custom fit) but only for breast cancer related lymphedema
- 6) First Nations and Inuit Health:** 4 compression garments per year plus bandaging supplies
- 7) Manitoba, Northwest Territories, New Brunswick, Newfoundland/Labrador, Nova Scotia, Prince Edward Island:** Limited coverage only for low-income patients receiving social services.