

December 18, 2015

The Right Honourable Justin Trudeau, P.C., MP.
Prime Minister of Canada
Office of the Prime Minister
80 Wellington Street
Ottawa, ON K1A 0A2

By Mail and Fax: 613-941-6900

Dear Prime Minister

Congratulations on your recent win of a majority government on the promise of "Real Change."

The lymphedema community of Canada is looking forward to some desperately needed real changes in the Canadian health care system particularly in regards to medical care coverage for the approximately 350,000 patients in Canada suffering from the condition.

We are writing to you on behalf of all Canadians living with lymphedema and would like to draw your attention to some serious issues with the Canada Health Act with regards to medical care coverage available to patients with lymphedema, including both adults and children.

About lymphedema

Lymphedema is an abnormal collection of high-protein fluid just beneath the skin. This chronic swelling, or *edema*, occurs most commonly in the arm or leg. **Lymphedema if untreated can be a progressive condition with physical, emotional, psychological and economic consequences.**

Lymphedema can be primary or secondary. Primary lymphedema results from congenital malformation or absence of the lymphatic system. Secondary lymphedema was thought to be primarily related to cancer and its treatment but newer evidence indicates that cancer treatment accounts for only half of all secondary lymphedema. Secondary lymphedema may also result from chronic venous disease, trauma, infection, non-cancer surgery and obesity. As obesity rates increase, the prevalence of secondary lymphedema will increase as well. Chronic edema/lymphedema can lead to irreversible malformation in the limb(s), life threatening cellulitis infections that require hospitalization, chronic pain, and other physical and mental disabilities that result in missed days of work, unemployment, isolation or depression, just to name a few. The effects can be debilitating for the individual, devastating for the family and costly for patients, their families, employers and the medical system.

There is no cure for lymphedema.

The international standard of care for this disease is Complete Decongestive Therapy (CDT), which consists of Manual Lymphatic Drainage (MLD) therapy, compression bandaging, skin care and special exercises. This therapy is performed by certified lymphedema therapists and costs approximately \$100 per hour with the accompanying custom medical compression garments costing hundreds of dollars each. For lymphedema patients, the financial burden of managing their condition can amount to thousands of dollars per year.

Here are some sample images of Canadians with lymphedema.



Issues

Despite the Canada Health Act and its promises of health care for all Canadians, the medical care coverage available to lymphedema patients varies significantly by province and territory. Many regions have no medical care coverage for lymphedema, while in other areas, some coverage exists but is clearly insufficient. In some provinces, limited financial support is available but only to those patients who developed lymphedema in the arm as a result of breast cancer, depriving those affected by congenital or hereditary lymphedema, or lymphedema caused by other types of cancer or trauma. These regional exclusionary reimbursement policies abandon a great majority of the population of lymphedema patients.

For many years, various charitable organizations throughout Canada have been advocating for their provincial/territorial governments to recognize lymphedema as a disease and obtain provincial and extended medical care coverage for lymphedema patients. The result has been an exhausted Canadian lymphedema community with limited results to show for their great efforts expended. It is also very frustrating for the Canadian lymphedema community to duplicate their efforts 13 times (10 provinces and 3 territories) in Canada.

Action required

We are appealing to the new Government of Canada for a commitment to examine these issues as part of its promised review of the Canadian health care system so that appropriate and equitable financial support is available for all lymphedema patients, **with all types of lymphedema (leg, genital, arm, trunk, head, and neck)** harmoniously across Canada.

There needs to consistent recognition across Canada of lymphedema and the validity for receiving medical care coverage for this disease. The Government of Canada has various tools, particularly its funding mechanism, to require all provincial and territorial governments to comply with this approach.

Benefits

The benefits of addressing these issues relating to lymphedema, is that harmonious, equitable support across Canada would lead to reduction of costs for government services including employment insurance, disability benefits, home care expenses, and reduced hospitalization costs. Greater productivity in Canadian workplaces and fewer hospital visits due to cellulitis would be tangible goals.

Conclusion

On behalf of the Canadian lymphedema community and all those living with lymphedema, we wish your government all the best, and we hope that we will see some real action with some real changes to support those affected by lymphedema and their caregivers.

We look forward to your timely response.

Regards,

Dr. David Keast, Chair
Anna Kennedy, Executive Director
Canadian Lymphedema Framework (CLF)

Alberta Lymphedema Association (ALA)
British Columbia Lymphedema Association (BCLA)
Lymphedema Association of Manitoba (LAM)
Saskatchewan Lymphedema Association (SASK)
Lymphedema Association of Ontario (LAO)
Lymphedema Association of Quebec (LAQ)
Atlantic Clinical Lymphedema Network (ACLN)
Lymphedema Association of Newfoundland and Labrador (LANL)

cc:

The Honourable Jane Philpott, MP, Government of Canada, Minister of Health
The Honourable Sarah Hoffman, Government of Alberta, Minister of Health
The Honourable Terry Lake, Government of British Columbia, Minister of Health
The Honourable Sharon Blady, Government of Manitoba, Minister of Health
The Honourable Victor Boudreau, Government of New Brunswick, Minister of Health
The Honourable Dr. John Haggie, Government of Newfoundland, Minister of Health
The Honourable Leo A. Glavine, Government of Nova Scotia, Minister of Health
The Honourable Dr. Eric Hoskins, Government of Ontario, Minister of Health
The Honourable Doug Currie, Government of Prince Edward Island, Minister of Health
The Honourable Gaetan Barrette, Government of Quebec, Minister of Health
The Honourable Dustin Duncan, Government of Saskatchewan, Minister of Health
The Honourable Glen Abernethy, Government of North West Territories, Minister of Health
The Honourable Paul Okalik, Government of Nunavut, Ministry of Health
The Honourable Mike Nixon, Government of Yukon, Ministry of Health