



BC LYMPHEDEMA
A S S O C I A T I O N
promoting healthy & hopeful living with Lymphedema

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Budget 2022 Consultation Submission

To:

Select Committee on Finance and Government Services: Budget 2022 Consultation

From:

BC Lymphedema Association

Date:

Sept 29, 2021

Submitted by:

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Our organization

The BC Lymphedema Association (BCLA) is a not-for-profit organization served by a team of volunteers, most of whom live with lymphedema. Lymphedema is a chronic, progressive disease requiring lifelong management. BCLA provides province-wide resources including information, education and support for people living with lymphatic disorders.

Our mission

We are the British Columbia provincial resource to promote optimal healthy living with lymphedema.

Lymphedema in British Columbia

In 2016 over 100,000 people in BC were living with lymphedema, a significant portion of the estimated 1 million Canadians with lymphedema. The results from a BCLA Lymphedema patient survey (2019) are summarized in three infographics, attached to this submission and on the BCLA website www.bclymph.org: Demographics, Quality of life and Financial impact.

Recommendations

1. Fund compression garments for patients with lymphatic disorders.
2. Provide diagnostic services and initial basic care within each health authority.

We are asking for financial aid to cover the cost of prescription compression garments for British Columbians who have lymphatic disorders or who are at risk of developing lymphedema. Compression garments are essential in the best-practice management of lymphatic disorders to attain and maintain basic functionality. For this request, we look forward to a response from PharmaCare to our 80-page *BCLA Application to PharmaCare: Financial Coverage for Prescription Compression Garments*, submitted to the Ministry of Health on June 18, 2021.

We ask that the BC health care system incorporate diagnostic services and initial care for patients with lymphatic disorders at specialized clinics within each regional health authority. In the longer term, care could expand to provide comprehensive resources, access to screening, early diagnosis, treatment options, and education in the daily management of lymphatic disorders.

Rationale

Patients in BC must currently pay for private specialized therapy and education. Many patients are on a limited income and cannot afford treatment or the necessary compression garments.

General practitioners do not often have the necessary training to differentiate lymphatic disorders from other forms of chronic edema. Patients must currently travel to Vancouver to see a single specialist for an accurate diagnosis. Once a patient has a diagnosis, there are currently no public medical facilities to teach patients the basics of edema management.

Lymphatic disorders can affect ability to work, leading to a reduced income and further limiting the ability to pay for treatment, purchase the essential compression garments required for improved functioning, or make a full contribution to society.

Cost savings

Specialized outpatient clinics in each health authority could generate substantial cost savings to the health care system by providing early intervention, therefore reducing emergency-room visits and lengthy hospital stays.

Many patients go undiagnosed or are diagnosed at a late stage, in which edema is more difficult to treat. When those with chronic edema from lymphatic dysfunction are not adequately treated, complications can lead to hospitalization, with increased financial costs to the health care system due to exploratory referrals and emergency hospitalization to treat infections.

We look forward to engaging with the BC Ministry of Health to address this challenging situation.

Submitted by Christine Chandler
President, on behalf of the BC Lymphedema Association

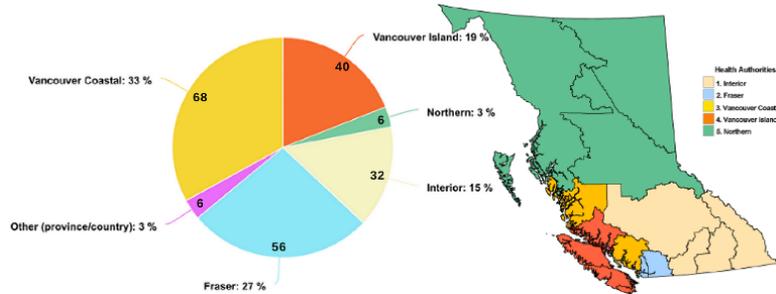
For personal stories of BC patients with lymphedema, see *Living with lymphedema in BC*, an 11-minute video released in March 2016 and filmed at the 2015 conference of the BC Lymphedema Association at BC Women's Hospital. The YouTube link is *Living with lymphedema in BC*:

www.youtube.com/watch?v=zXDZqFsV8J4

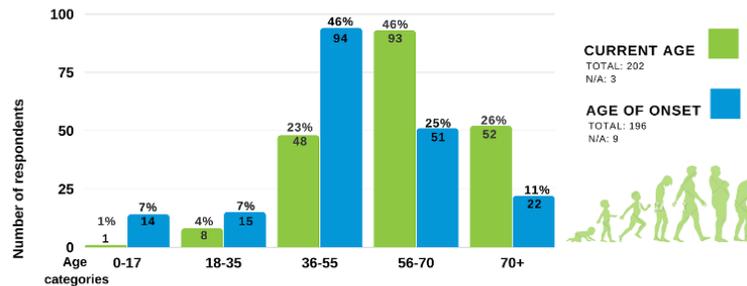
- Attached:** BC Lymphedema patient survey (2019)
- Demographics
 - Quality of life
 - Financial impact

LYMPHEDEMA PATIENT SURVEY (2019) DEMOGRAPHICS 205 respondents

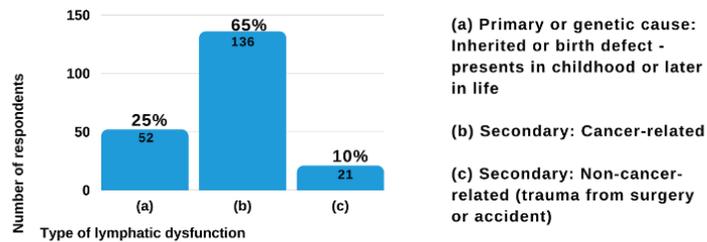
GEOGRAPHIC DISTRIBUTION (by Health Authority)



AGE DISTRIBUTION

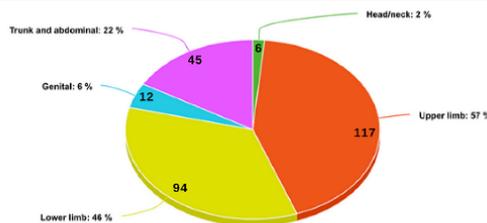


TYPE OF LYMPHATIC DYSFUNCTION*

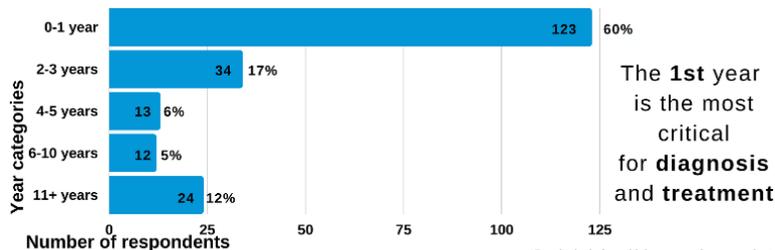


21% (43) of respondents also have lipedema

REGION ON BODY*



TIME BEFORE DIAGNOSIS & TREATMENT

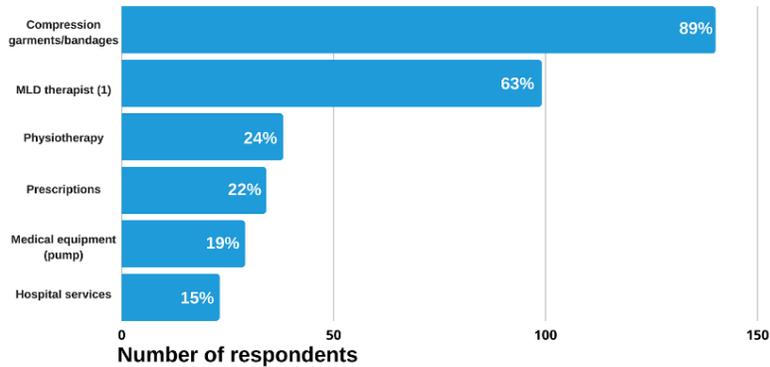


*Results include multiple answers by respondents

LYMPHEDEMA PATIENT SURVEY (2019) QUALITY OF LIFE

158 respondents*

NECESSARY MEDICAL SERVICES and TREATMENTS*

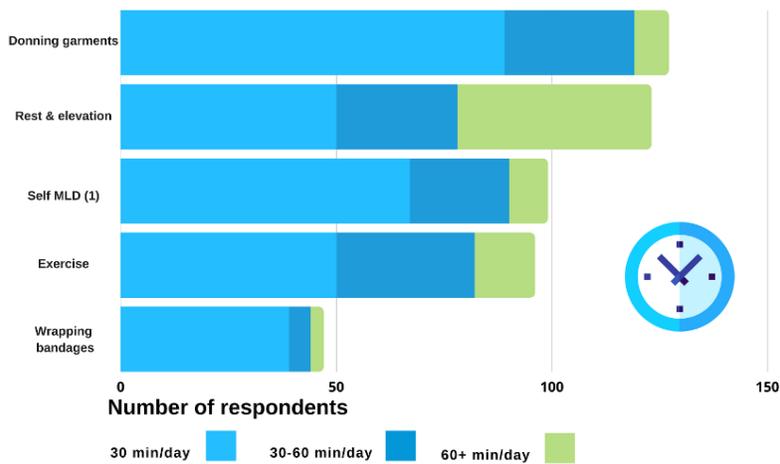


(1) MLD = Manual lymph drainage

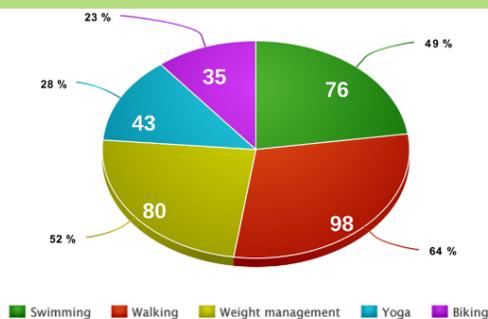
DAILY MANAGEMENT of LYMPHEDEMA*

60% of respondents spend up to 1 hour/day

44% spend 2+ hours/day on self-management techniques



EFFECTIVE EXERCISE to MANAGE EDEMA*



*Results include multiple answers by respondents

LYMPHEDEMA PATIENT SURVEY (2019) FINANCIAL IMPACT

158 respondents

COST OF COMPRESSION

Annual cost of compression garments range in price from **\$250 - \$2500**

Prices depend on ready-made vs. custom, lymphedema stage, patient's ability, and fabric/style/brand

MLD treatments range from **\$95 - \$260** per 60-90 min. session*

ABILITY TO PAY FOR TREATMENT

30% of respondents do not have extended health coverage

Lack of extended health coverage is affected by:



Retirement



Unable to work



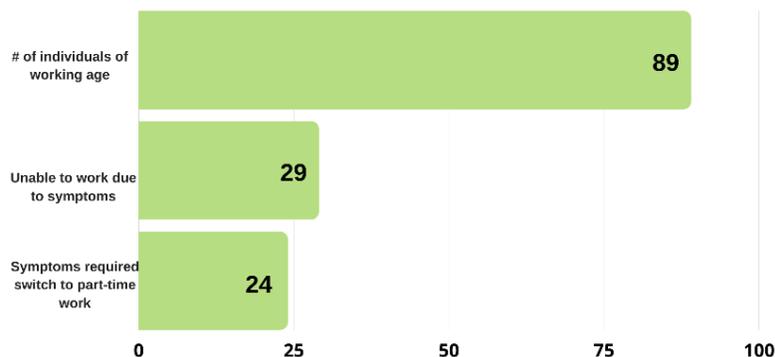
Part-time work



No workplace benefits

EFFECTS OF LYMPHEDEMA ON WORK

19% of respondents are unable to work



Over **65%** (100) of respondents reported an impact on their ability to work due to:



Climbing stairs



Pain in affected areas



Heavy lifting



Difficulty walking