



Living with lymphedema : Learning to take charge



Welcome

This booklet is intended for someone who has just learned that they have lymphedema and those who may still have questions about how to live with this chronic condition. The information has been presented in a way that is easy to read and understand. It offers suggestions and information that are based on available research and expert advice. We recommend that you also discuss your lymphedema with a qualified health professional.

Acknowledgements

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A diagnosis of lymphedema can have a significant impact on your life. The key to success in managing this condition is by learning as much as you can, so you can take charge and practice self-care. We hope this booklet not only informs you, but inspires and encourages you to lead a healthy lifestyle that will improve your quality of life while living with lymphedema.

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What is lymphedema?

Lymphedema (lim-fa-DEE-ma): **chronic swelling** (edema) caused by a buildup of fluid (lymph).

Who develops lymphedema and why?

Lymphedema affects men, women and children of all ages.

Primary lymphedema occurs when a person is born with a faulty lymphatic system. Signs of lymphedema may be present from birth or develop during puberty or later. The later development may be due to changes in hormones or body weight that put more of a burden on the lymphatic system.

Primary lymphedema is more common in women than men. It occurs mainly in the legs.

Secondary lymphedema is more common than primary lymphedema. It occurs when a person's lymphatic system is damaged by surgery, radiation therapy or severe injury (e.g. a burn or skin infection). It can develop a short time after the damage occurs or many years later.

People who are treated for cancer (e.g. breast, prostate, gynecological, melanoma, lymphoma or other cancers) have a lifelong risk for lymphedema if they have had lymph nodes or vessels removed or damaged during treatment.

Secondary lymphedema may also develop due to surgery not related to cancer or other causes such as severe trauma, recurring infections, venous insufficiency

or filariasis (a severe type of lymphedema caused by mosquito bites in some tropical countries).

Lymphedema due to "secondary" causes often develops in the part of the body where the lymphatic system is faulty or damaged. The more damage there is the higher your risk for lymphedema.



Living with lymphedema

Lymphedema is a lifelong condition caused by a buildup of fluid. This happens when the lymphatic system is either faulty or damaged and cannot function as normal. It leads to chronic (long-lasting) swelling in the tissues where the lymph flow is blocked. Most often the swelling is in an arm or leg, but it can also be in the breast, trunk, genitals or head and neck.

Early diagnosis and treatment is the best way to manage lymphedema.

What is the lymphatic system?

The lymphatic system is part of your body's circulatory and immune systems. It helps to keep your body healthy by

- Keeping a healthy balance of fluid in the tissues
- Transporting proteins and digested fats to provide your cells with nutrients
- Helping to fight infection by removing bacteria, viruses and other germs

What does it do?

It moves lymph fluid towards the heart through a network of lymph vessels and lymph nodes.

- Lymph fluid is a clear liquid made up of water, proteins and white blood cells that fight infection
- Lymph vessels transport and drain lymph fluid back to the blood system and the heart
- Lymph nodes filter out bacteria, viruses, other germs and waste to keep you healthy

What helps lymph flow?

- Moving your muscles
- Deep breathing
- A special kind of gentle massage called manual lymphatic drainage

What restricts lymph flow?

- Your body's natural bottlenecks, where it bends at your knee, ankle, armpit, elbow or groin

- Tissue injury, where you have bruising, swelling or scarring

What causes swelling?

- When your lymphatic system is healthy, your body moves the "lymph load" well, and there is usually no tissue swelling
- If your body is not able to move the "lymph load" well, and there is a buildup of fluid, tissue swelling will occur

When swelling occurs, the health of tissue and cells in that area gets worse, and the risk for infection increases. Early diagnosis and treatment by a lymphedema therapist is the best way to manage lymphedema.

How many lymph nodes do I have?

There are hundreds of lymph nodes in your body. They are in clusters in your neck, head, armpits, stomach and groin. When you're fighting an infection, you may feel lymph nodes swell up in your neck, just below your jawbone. The number, size and location of lymph nodes vary from person to person. This may be why one person develops lymphedema and another doesn't, even if they both have similar risk factors.

Your lymph nodes are as unique as you are!



What increases the risk for lymphedema?

The risk for lymphedema depends on a number of factors, including:

- A family history of chronic (long-lasting) swelling
- If you had surgery, the number, size and location of lymph nodes removed or damaged
- If you had radiation therapy or an injury, the degree of damage to your lymphatic system
- Having chronic venous disease
- Having a history of skin infections, including cellulitis (see page 16)
- Being overweight and/or inactive can add to these risk factors

Having a risk factor doesn't mean a person will develop lymphedema. But it does put them at a higher risk. In fact, if your lymphatic system is faulty or damaged, you have a lifetime risk for lymphedema.

Where does lymphedema develop?

Lymphedema can develop in any part of the body where the lymphatic system is blocked. For example, if you had lymph nodes removed from your armpit to treat breast cancer, you may develop lymphedema in the arm, chest or back on that side.

We can't predict who's going to develop lymphedema.

- Your body may heal well after treatment and be able to manage the lymph flow in the damaged area
- Or the extent of damage to your lymphatic system may combine with other risk factors and trigger lymphedema – during treatment or many years later

Lymphedema is a lifelong condition. It cannot be prevented or cured, but it can be managed. Early diagnosis and treatment by a lymphedema therapist is the best way to manage lymphedema.



Cancer treatment and lymphedema risk

In Canada, the most common cause of secondary lymphedema is cancer treatment (e.g. for cancers of the breast or prostate, gynecological cancers, melanoma, lymphoma or other cancers). Cancer surgery and radiation therapy may alter the lymphatic system if lymph nodes and vessels are removed or damaged during treatment.

Some cancer treatment leads to a lifetime risk for lymphedema.

What are the signs and symptoms?

The early signs and symptoms of lymphedema include:

- Swelling that can be sudden, gradual or occasional – most often the swelling is in an arm or leg, but it can also be in the chest, trunk of the body, head or neck
- Clothing, shoes or rings/watch may feel tighter, but not due to weight gain
- Feelings of heaviness, tightness, fullness or heat in the affected area
- Aches, shooting pain or pins and needles in the affected area
- Skin may feel tight or stretched, and sometimes its texture feels thicker

Can lymphedema get worse if not treated?

As it gets worse, signs and symptoms include:

- Any of the early signs listed above
- Repeat skin infections in the affected area
- Clear fluid leaking from the skin
- Hardened areas under the skin
- Skin changes such as thickening, dry and/or rough areas, colour changes or hard, blister-like nodules on the skin's surface
- Feelings of pins and needles in fingers or toes
- Decreased mobility and function in the joints of swollen limbs

- If you wear a compression garment that has become too tight, but not due to weight gain

If you notice signs of lymphedema, see a health professional as soon as you can. With early diagnosis and treatment, you can control lymphedema and lower your risk of it getting worse.

Contact your provincial association for the full version of this booklet

Watch out for signs of skin infection (cellulitis).

Cellulitis is a sudden, non-contagious skin infection. It is treated with antibiotics and must be treated right away as it can spread quickly. When it is severe, people may spend time in hospital to have the infection treated.

For signs and symptoms of cellulitis, see page 16.



Where can I go for support?

You are not alone

Being diagnosed with lymphedema can be emotional. You may feel angry, sad or upset about how lymphedema affects your life. You may feel embarrassed about changes to your body and how you see yourself. At first, you may feel discomfort at having to wear compression bandaging or garments under your clothing. You may also resent the time it takes for self-care each day, the costs of treatment, or how your condition reminds you of what caused it. If you worry about what you could have done to prevent lymphedema, don't blame yourself – you did nothing wrong.

There is support for you

Across Canada there are trained lymphedema therapists, patient-focused organizations and other people living with lymphedema who can help you. Canada has one national organization and seven regional associations that support people living with lymphedema. Contact your region's lymphedema association for listings of certified therapists, programs and services in your area. They'll be able to answer your questions and connect you with people who are living with lymphedema (see page 19). They know what you're going through – because they've been there too.

Hope for the future

Research is helping us better understand lymphedema. Advances in diagnostic imaging, surgical techniques, possible drugs, and our ability to predict lymphedema give us hope that how we detect, treat and manage it in the future will improve greatly.

Self support

Many people with lymphedema lead full and active lives. With the help of some lifestyle changes and taking care of yourself each day, you'll learn how best to manage your lymphedema. Try not to expect too much too quickly – doing that just stresses out your lymphatic system and your mind!

Be kind to yourself.



Contact your provincial association for the full version of this booklet

Resources

Provincial Associations

Alberta: Alberta Lymphedema Association
www.albertalymphedema.com

Atlantic Region: Atlantic Clinical Lymphedema Association
www.atlanticlymph.ca

British Columbia: BC Lymphedema Association
www.bclymph.org

Manitoba: Lymphedema Association of Manitoba
www.lymphmanitoba.ca

Newfoundland and Labrador: Lymphedema Association of Newfoundland and Labrador
www.lymphnl.com

Ontario: Lymphedema Association of Ontario
www.lymphontario.ca

Quebec: Lymphedema Association of Quebec
www.infolympho.ca

Saskatchewan: Lymphedema Association of Saskatchewan Inc.
www.sasklymph.ca

Websites

Canadian Lymphedema Framework
www.canadalymph.ca

International Lymphoedema Framework
www.lympho.org

Lymphatic Education and Research Foundation
www.lymphaticresearch.org

National Lymphedema Network
www.lymphnet.org

Lymphedema for Kids
www.lymph4kidz.com/

Teen website for lymphedema
www.lymteen.co.uk/pages/home

Lymph Notes
www.lymphnotes.org

StepUp-SpeakOut
www.stepup-speakout.org

Books

100 Questions & Answers About Lymphedema
By Saskia R. J. Thiadens, Paula J. Stewart & Nicole L. Stout

Living Well With Lymphedema
By Ann B. Ehrlich, Alma Vinjé-Harrewijn & Elizabeth J. McMahon

Lymphedema Caregiver's Guide
By Mary Kathleen Kearse, Elizabeth Jane McMahon & Ann B. Ehrlich

Lymphedema: Understanding and Managing Lymphedema After Cancer Treatment
By American Cancer Society

Overcoming the Emotional Challenges of Lymphedema
By Elizabeth J. McMahon

Voices of Lymphedema
By Calina Burns, Ann B. Ehrlich & Elizabeth J. McMahon

For suggested videos and archived *Pathways* articles, visit www.canadalymph.ca

The Canadian Lymphedema

Framework (CLF) is a non-profit collaboration among health professionals, researchers, community based organizations, industry partners, and patients to improve the standards of lymphedema care in Canada. Founded in 2009, the CLF is the only Canadian organization working nationally to address lymphedema concerns. It is a partner of the International Lymphoedema Framework – an international initiative to promote research, best practice guidelines, and lymphedema clinical development around the world.

Our vision and philosophy

Comprehensive effective treatment for lymphedema and related disorders will be accessible to all persons across Canada.

- Effective treatment is based on best practice guidelines
- Lymphedema treatment must be fully covered or reimbursed
- Patient views are integral to all development of care
- Contributing to the rapidly growing evidence base is paramount
- International collaboration will increase global awareness of the importance of lymphedema in healthcare

For more information or to acquire the full version of this booklet, please contact your provincial lymphedema association.



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