Information for patients & families

Understanding Cancer-Related Lymphedema



Symptom Management – Rehabilitation Oncology



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This booklet provides information about cancer-related lymphedema and suggestions on how to manage this chronic condition, while allowing you to lead a full and healthy lifestyle.

What is lymphedema?

Lymphedema is the build up of lymph fluid in your tissues. This leads to swelling (edema) in the body.

Cancer-related lymphedema is called 'secondary lymphedema' as it can develop from cancer treatments, surgery, or from the cancer itself.

Swelling is most common in the arms and legs, but can also happen in other parts of the body like the breast, chest and genitals.





Lymphedema can range from mild swelling that comes and goes, to more long-lasting swelling in one or more areas of the body where the lymph flow was interrupted by the cancer or its treatments

In most cases, lymphedema is a lifelong condition. A good understanding of lymphedema will help you better manage and control the condition.

What is the lymphatic system?

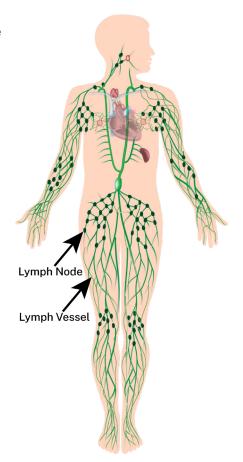
The lymphatic system is part of the circulatory and immune system.

In this system, **lymph** fluid is drained from our body tissues and flows back into our blood through a system of vessels and nodes.

The lymphatic system:

- Keeps a balance of fluid in the tissues.
- Helps fight infection by filtering out germs and waste to keep you healthy.
- Moves proteins and digested fats.

If lymph nodes are damaged or removed, lymph fluid can back-up and cause the tissues to swell.



Lymph Nodes

A lymph node is a bean shaped organ that filters the fluid flowing through the lymphatic system. The fluid is filtered with the help of lymphocytes (white blood cells) that scan the fluid for germs and viruses. Lymph nodes are in clusters all over the body and are connected together by lymph vessels.

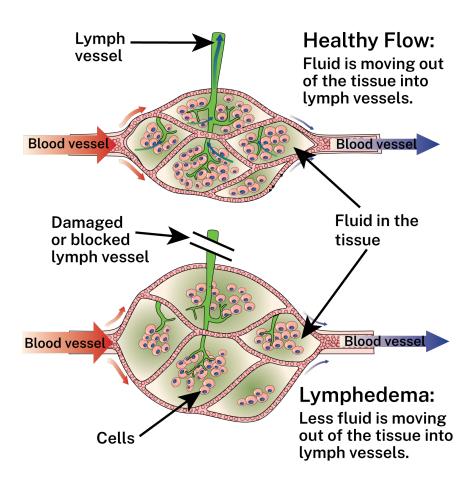
Lymph Vessels

Lymph vessels are channels that collect lymph fluid from our tissue and carry the fluid back to the bloodstream.

How does lymph flow through the body?

Fluid flows into our tissues from the blood stream. Most of the fluid is picked up and removed from the tissues by tiny lymph vessels.

Once fluid enters a lymph vessel, it is called **lymph**. Lymph moves from small vessels to larger vessels, and is returned to the blood stream. Movement of our muscles (exercise) helps move lymph though our body.



What causes lymphedema?

In cancer patients, lymphedema is caused by:

- the surgical removal of lymph nodes (cancer surgery)
- damage to lymph nodes and vessels by cancer treatments like radiation therapy
- · the cancer itself

The swelling from cancer-related lymphedema only occurs in the part of the body where the lymph flow is interrupted.

Lymphedema is a transportation problem

Lymphedema is a fluid transportation problem — the fluid isn't moving well, so it stays in the tissue longer, causing it to swell.

If we think of lymphedema like the movement of cars through a city—when the highway lanes are all open, traffic flows well.

Surgery is like having a road block up ahead. Cars have to find another route to get around. Our body is smart — lymph fluid will find another route to move through the body, but this takes more time.

Radiation therapy causes the tissues in the area to stiffen. The stiffened tissue is like having bad weather conditions—cars slow down and take longer to move around.



What are the signs and symptoms of lymphedema?

Only some people develop large swollen limbs like the ones shown in the pictures in this booklet. Signs and symptoms of lymphedema are different for everyone, and can include:

- · Sudden, gradual, or occasional swelling.
- · A heaviness or fullness feeling.
- · Clothing, shoes, rings, or watches feeling tighter.
- Pain or discomfort.
- Less range of motion, or ability to move the joints.
- · Skin that feels tight or stretched.
- Skin that starts to feel thicker or hard.
- · Infection of the skin (called cellulitis).

How is lymphedema treated?

Lymphedema is a long-term condition, so you will need to learn ways to manage it. Goals of treatment include:

- Reducing or softening the swelling
- Preventing the lymphedema from getting worse
- · Preventing infection
- · Relieving pain or discomfort
- Improving movement and use of the arm or leg

Lymphedema is treated in 2 phases:

- Intensive reduction phase: aims to reduce the swelling and may involve compression bandaging, skin care, and exercise.
- Maintenance phase: aims to maintain the reduced size of your limb. It may involve daytime compression, skin care, exercise, lymphedema pump, and self-massage.

Compression Therapy

Compression therapy is an important part of lymphedema management. Compression therapy uses daytime garments, night systems, and bandaging to apply pressure to a swollen area. This compression helps:



- · to move lymph fluid out of that area
- your muscles move the lymph fluid out of the area better

The goal is to make the swollen body part smaller, or keep it from getting bigger.

Compression Bandaging

Bandaging is a treatment to help reduce swelling in a limb. Compression bandages are put on the limb and worn day and night. There are different ways to wrap a limb to reduce the swelling, and your lymphedema specialist will talk to you about your options.

Bandaging can:

- Help you before you get a compression garment.
- Be used at night for maintenance.





Daytime Garments

Compression garments are used to keep swelling under control. Depending on the location of swelling, you may need stockings, sleeves, gloves, and/or bra, camisole, or gauntlet.

Your therapist or a qualified fitter can help you find a garment that is comfortable and effective.

Compression garments are:

- made of elasticized fabrics of varying pressures
- ready-made or custom fit
- worn in the daytime, or as prescribed
- worn when flying swelling may worsen at high altitudes
- replaced every 4–6 months if worn daily
- replaced if they no longer fit or are worn out

Night System

Night compression systems are available for those who may benefit from wearing compression through the night.



Practice Good Skin Care

People with lymphedema are at risk for cellulitis and other skin infections which can make swelling worse. Practice good skin care to lower risk of infection:

- Keep your skin clean and well moisturized. Use a good quality and unscented moisturizer.
- Protect your skin to avoid getting open areas like cuts, scratches, burns and bug bites.
 - If you get an open area, apply antibiotic ointment and cover with a Band-Aid.
- Use sunscreen and insect repellent.
- Avoid cutting your cuticles and take care when having a manicure or pedicure.
- Use an electric razor if you need to shave the area.
- Get treated for skin conditions like athlete's foot, dermatitis, or fungal infections.
- If possible, do not have IV's, vaccinations, or blood draws in the area of the body that has lymphedema.

Know the signs of infection (cellulitis) and see a doctor if you think you have an infection.

Signs of Infection:

- · Redness, red streaks, or rash
- Pain or tenderness
- · Skin feels warm or hot to touch
- Sudden onset or increase in swelling Infection can progress quickly. If you feel flu-like symptoms, fever or chills, general

flu-like symptoms, fever or chills, general aching, and weakness, go to your local Emergency Department.

Exercise and Active Lifestyle

Regular exercise is important for treating cancer-related lymphedema. Exercise **should not** be avoided and will be an important part of your lymphedema treatment plan.

- By moving your muscles and breathing more deeply, you stimulate your lymphatic system and help lymph fluid flow.
- Resistance (strength) exercises can improve symptoms of lymphedema, improve quality of life, and increase your muscular strength.
- Range of motion exercises can help with tissue stiffness from surgery and radiation therapy. Working towards full mobility of your muscles and joints can improve your lymph flow.

Your therapist may show you some exercises that can be helpful for lymphedema. Remember to:

- Avoid sitting for long periods of time.
- · Get up and move around throughout the day.
- Add activity and exercise slowly and build up to doing more.
- Wear a well-fitting compression garment when exercising.
- Do not exercise to the point of your limb feeling stiff or sore.
- Monitor how your limb responds to exercise and adjust as needed.

Some exercises to help you get started can be found on YouTube by searching:

- "Cancer Rehab PT exercises for arm lymphedema"
- "Cancer Rehab PT exercises for leg lymphedema"
- "Cancer Research UK arm exercises for lymphoedema"
- "Cancer Research UK leg exercises for lymphoedema"

Being active during cancer treatment

Research shows that exercise is the best way to improve and build up your energy, and reduce your fatigue. The great thing about exercise is that our bodies adapt to it. If you aren't used to exercising, start slowly:

- Do short sessions more often.
- Try low-to-moderate intensity activities (walking, yoga) for 5–10 minutes at a time.
- Build up to exercising 30 minutes, 5 days a week.
- Include some strength training exercises 2 days a week.

As you build up your strength, aim for 150 minutes (2.5 hours) of low-to-moderate intensity exercise per week. You may not be able to meet this goal while on treatment, but don't get discouraged.

The most important thing is to be as active as you can. The activities shouldn't be too easy or too hard. Make sure you can still talk comfortably while you exercise. Benefits of exercise include:

- More energy, less fatigue
- Less depression and anxiety
- A feeling of well-being
- Stronger muscles
- · Better appetite
- Better sleep



Other Helpful Tips:

- Work towards a healthy body weight. Obesity is a risk factor for lymphedema. Managing your weight may make lymphedema better.
- Be cautious with heat sources that can cause general swelling, like hot tubs, saunas, and steam rooms. Pay attention to how your body responds to heat.
- Minimize outdoor activities during the "heat of the day."
- Wear sunscreen to avoid sunburns.
- If possible, avoid heating pads or hot packs on your swollen limb.
- Avoid clothes that may block your lymph flow. Wear:
 - ☐ Bras with wide straps (for arm lymphedema)
 - ☐ Underwear with loose leg openings (for leg lymphedema)
- Avoid tight jewelry (rings, watches) or clothing on the affected limb.
- If possible, have blood pressure taken on the opposite arm.



Other treatment options

Current research shows that **compression** and **exercise are the most helpful treatments** to improve lymphedema.

Currently the evidence isn't clear about who may benefit from Manual Lymphatic Drainage (MLD), pneumatic compression pump, or surgery for their lymphedema. Talk to your healthcare provider if you have questions about these options.

Manual lymphatic drainage (MLD)

MLD is a gentle massage technique to improve lymph flow and unblock or soften hard or swollen tissue.

- Some people find MLD helpful for softening an area and/or to provide comfort.
- Lymphedema therapists in Cancer Care Alberta do not use MLD as part of regular lymphedema management, but they can teach you how to do self-lymphatic massage. You can do this at home if you find it helpful.

If you are interested, there are therapists in the community who provide MLD.

Pneumatic Compression Pump

This is a device where the swollen limb is put into an inflatable sleeve. The device pumps air into the sleeve to compress the limb, and releases it during a timed cycle. Each session takes about 1–2 hours.

Ask your healthcare provider for guidance and instructions before buying or using this type of device.

Surgery (e.g. Liposuction, lymphovenous bypass)
Surgery is not standard treatment for lymphedema. Talk to
your doctor if this is something you are interested in learning
more about.

Resources and funding

Cancer Care Alberta (CCA) Rehabilitation Oncology

CCA provides cancer-related lymphedema services in several cancer centers in Alberta. A referral from a doctor or nurse practitioner is required.

Your visit will include an assessment, treatment, and monitoring by physiotherapists or occupational therapists trained in lymphedema management.



Alberta Aids to Daily Living

Alberta Aids to Daily Living (AADL) is a provincial program that helps to reduce the cost of compression garments for people without 100% coverage from an extended health benefit plan. You **need to be added** to the AADL program by your therapist.

AADL covers:

- If you have lymphedema in your arm, 75% of a base price of either 2 custom, or 3 ready-made garments per year.
- If you have lymphedema in your leg(s), 75% of a base price of 2–3 pairs of stockings per year.

Low-income individuals may qualify for 100% coverage.

Insurance and Health Benefits

Third Party Insurance

Third party insurance may cover part, or all the cost of your compression garments. Call your insurance company to get information specific to your plan.

Other therapists may be available in the community to treat your lymphedema. There will be a cost for this service, but third-party insurance may cover some of those costs.

NIHB (Non-Insured Health Benefits)

Provides eligible Indigenous, First Nations and Inuit clients with coverage for a range of health benefits that are not covered through other social programs, private insurance plans, or provincial health insurance.

Online Resources

Alberta Lymphedema Association

www.albertalymphedema.com

Canadian Cancer Society

www.cancer.ca

Canadian Lymphedema Framework

• www.canadalymph.ca

International Lymphedema Framework

www.lympho.org

Frequently Asked Questions

Can I take a water pill to help my lymphedema?

Water pills do not help with lymphedema because lymphedema is a drainage problem, not a problem from having too much fluid.

Will my lymphedema ever go away?

Lymphedema is a chronic (long-term) condition. The goal of treatment is not to cure the lymphedema but to manage it well.

Can you drain lymphedema using a needle?

This might be an option for comfort and symptom relief for some palliative patients.

Will strength training make my lymphedema worse?

Once your lymphedema is under control, adding weights to your exercise routine in a gradual and consistent way will not make your lymphedema worse. Research suggests that regular weight training can decrease the severity of lymphedema flare-ups.



Should I stop eating salty foods or using salt?

Most people eat too much salt. Try to reduce:

- Eating salty and/or processed foods
- · How much sugar you eat
- How much alcohol you drink

Remember, maintaining a healthy body weight is part of managing your lymphedema. It's important to eat a balanced diet.

Should I avoid getting blood work done on my affected side?

If possible, have blood work taken from your unaffected side. This will help reduce your risk of infection.

Can I go to the beach or pool without compression?

You do not need your compression when you are in the water. In fact, the water acts like your compression and can help move the lymph fluid while you stay cool and have fun.

You should wear your compression when you are dried off and out of the water.



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The information is to be updated every 3 years, or as new clinical evidence emerges. If there are any concerns or updates with this information, please email cancerpatienteducation@ahs.ca.



Important things to remember:

Lymphedema is a fluid transportation problem

Compression garments are an important part of lymphedema management.

Exercise is important for your health and treating cancer-related lymphedema.

Get your information from trusted websites and resources

For other Cancer Care Alberta resources, visit cancercarealberta.ca



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