



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.

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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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for their creative solutions. A special thanks to Marie-Eve Letellier and Dr. Anna Towers, who are responsible for this updated revision with extra focus on compression and self-care.

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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, obesity

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 people in Canada have lymphedema?

About 1 million Canadians have chronic edema or lymphedema, and the number is on the rise. Previously it was thought that cancer-related lymphedema was the most common form. However, recent data show that many people also have lymphedema as a complication of chronic venous disease, non-cancer related surgery or morbid obesity.

Many people are undiagnosed and untreated.



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 17)
- 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, a 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.



Watch out for signs of skin infection (cellulitis).

Cellulitis is a sudden, non-contagious bacterial infection of tissues under the skin. People with lymphedema are at a greater risk of cellulitis. The infection must be treated right away with antibiotics 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 17.

How is lymphedema diagnosed?

If you notice signs of lymphedema, see a health professional as soon as you can. They will review your medical history, examine any visible swelling or other symptoms, perform limb volume measurements and check for lymphedema with Stemmer's and pitting tests. They will also do tests to rule out other causes of swelling (e.g. early stages of venous disease, varicose veins, thyroid issues, lipedema or other causes). Sometimes an imaging test will be done to show where lymph flow is blocked.

Stemmer's test

The fold of skin at the base of the second toe or middle finger is pinched. If it is easy to pinch and lift a fold of skin less than 2-3 mm, this is not a sign of lymphedema. If the skin fold is thicker than 3 mm or you are unable to lift a skin fold, this may be a sign of lymphedema.

Pitting test

A thumb or finger is gently pressed into the swelling and held for 30 seconds. If it leaves an indent for some time, this is a sign of lymphedema.

If the assessment suggests lymphedema, you must be referred to a certified lymphedema therapist (see page 9).

Measuring lymphedema

A lymphedema therapist will measure the affected limb/area to calculate its volume. There is no standard method, but measurements are taken in the same place(s) each time, to show if swelling has increased, been stable or reduced. To help monitor your condition, a therapist may teach you and/or family members how to take your own measurements. Tracking measurements helps you take charge of lymphedema.



What is lipedema?

Lipedema is a condition that affects some women. It is caused when higher than normal fat deposits build up on the buttocks, legs and ankles (but not the feet). Like lymphedema, lipedema is a lifelong condition. But they are different conditions and lipedema is often misdiagnosed as lymphedema.

It is important for a health professional to give you the proper diagnosis.

What are the stages of lymphedema?

Lymphedema is a lifelong condition that will get worse over time if it is left untreated or not managed well.

There are four stages of lymphedema. The signs of lymphedema and treatment needed are different at each stage. A lymphedema therapist will assess your stage. This helps the therapist develop the best treatment plan for you.

Stage 0: Latent/Early (no visible swelling)

There are subtle changes in the tissue, skin and how an affected limb feels, but no visible sign of swelling. This stage may continue for months or years before visible swelling occurs.

Stage 1: Mild (swelling can be reversed)

The first visible signs of swelling show at this stage. The swelling is soft and may indent with thumb pressure (called 'pitting'). When the affected arm or leg is raised, the swelling tends to reduce. The swelling often comes on by the evening but has gone by morning.

Stage 2: Moderate (swelling cannot be reversed)

Raising the affected limb no longer reduces tissue swelling at this stage. Pitting may still occur, but more pressure may be required to show an indent. In later stage 2, pitting may not be possible due to a buildup of fatty tissue or tissue hardening (called fibrosis).

Stage 3: Advanced (swelling is extreme)

The skin has hardened (fibrotic) and pitting is no longer possible. The skin may also be drier and thicker with warty growths and leakage of lymph fluid (called lymphorrhea).

A proper diagnosis and assessment of lymphedema is the first step toward effective treatment.



How is lymphedema staged?

To stage lymphedema, a certified lymphedema therapist will consider the following: the degree of swelling, the health of underlying tissue, and whether you have had infections such as cellulitis, inflammation or other complications.

Staging helps the therapist develop the best treatment plan for you.

How is lymphedema assessed?

At your first appointment, the lymphedema therapist will ask about your medical history, take limb measurements and assess your skin in the affected area. This assessment will be the basis for your treatment plan.

Your treatment plan will also depend on your stage of lymphedema and phase of treatment.

Intensive phase: Aims to reduce swelling with compression bandaging, lymphatic drainage, good skin care and exercise. The lymphedema therapist is very involved.

Maintenance phase: Aims to keep your condition stable with a compression garment and ongoing skin care, regular exercise and self-massage for lymphatic drainage. You will take charge of your care and will learn what works best for you.

The best treatment is decongestive lymphatic therapy from a certified lymphedema therapist:

- **Compression therapy** to reduce and contain swelling
- **Lymphatic drainage** (a special type of gentle massage) to improve lymph flow, direct fluid to other drainage pathways, and unblock or soften hard tissue
- **Skin care** education on how to avoid infection
- **Exercises** to promote lymphatic function and flow

Your therapist may also suggest that you speak to other health professionals (e.g. a nutritionist, dietitian, medical exercise specialist or social worker) for a fuller assessment or to help you take care of your health.

Who treats lymphedema in Canada?

To assess and treat lymphedema in Canada, therapists must be certified. Canadian certified lymphedema therapists are nurses, physiotherapists, occupational therapists and registered massage therapists who meet the Canadian Lymphedema Framework's national training standards. To certify, lymphedema therapists train for at least 135 hours with a recognized school.



How do I find a lymphedema therapist?

Most therapists in Canada work in private clinics. Some cancer centres offer lymphedema services, but they are usually only accessible to their own patients.

To find a certified lymphedema therapist in your area, contact your provincial lymphedema association (see page 23).

Treatment: Compression therapy

Compression therapy uses special bandages and garments to reduce and control swelling. The type of compression therapy you need will be unique to you and will depend on whether the swelling is mild, moderate or severe. It will also depend on your stage and phase of treatment.

Compression bandages

There are two approaches to compression bandaging, to help reduce swelling:

- One approach is to apply bandages daily, which can be washed, hung to dry and reused
- The other is a two-layer cohesive bandage that is applied once or twice a week; it can be left on for several days, but it cannot be reused

Compression garments

Different types of garments are used to keep swelling under control:

- Compression sleeves, stockings or gauntlets with varying compression levels are made for lymphedema in different parts of the body
- Different garments for day and night wear
- Range of colours and styles in circular or flat knit knitted material
- Ready-made and custom-made garments are available from pharmacies and stores that specialize in compression wear

Often, people with mild to moderate lymphedema need only wear compression garments during the day. For people with moderate or severe lymphedema, a therapist might recommend both night and day compression garments.



A prescription starts the process

Compression garments are prescribed by a medical doctor, often based on the recommendation of your lymphedema therapist. Whether you need ready-made or custom-made garments, go to a qualified garment fitter.

There are a great variety of fabrics, styles and colours to choose from.

Treatment: Buying compression garments

Getting used to your compression routine may seem a bit daunting at first. If you are looking for your first compression garment or haven't yet found the right garment, you may have a lot of questions. Most people do. Finding answers to your questions is part of the process of adjusting to life with lymphedema – and an important step in learning how to take charge of it.

Getting a prescription

First things first: compression garments are prescribed by a medical doctor, often based on the recommendation of your lymphedema therapist. All prescriptions will include the following items at least:

- Your name
- Diagnosis (e.g. primary lymphedema, lymphedema post-breast cancer)
- Affected side (e.g. left, right, bilateral)
- Affected body part (e.g. arm, leg, genitals)
- Garment (e.g. knee stocking, sleeve and/or glove)
- Garment fabric (e.g. circular knit or flat knit)
- Garment type (e.g. ready-made/standard or custom-made)
- Level of compression (e.g. 15-20 mmHg, 20-30 mmHg, 30-40 mmHg, 40-50 mmHg)
- Special considerations if needed (e.g. silver for wound management, silk insert to reduce friction at the thumb/elbow)

You may need a separate prescription for compression bandages, padding material or aids for putting on and taking off garments.

Getting fitted for a garment

Many pharmacies and drug stores sell compression garments. However, they are low grade compression garments and are not designed for lymphedema care.

For expert advice, visit a qualified garment fitter at a specialty store. Garment fitters often work with lymphedema therapists. They are knowledgeable about the types of products available and have been trained to measure an affected limb for a garment with the right fit and level of compression. If compression garments are covered by your provincial or territorial health plan, find out if the plan requires you to buy garments from certain stores and fitters.

Visit a qualified fitter at a specialty store

Speak to your lymphedema therapist or contact your provincial lymphedema association for advice about fitters and stores before making any purchases.

Buy smart.



Treatment: Choosing a garment

A qualified garment fitter will present you with a choice of different fabric types and colours. Be aware that even if you like the feel of a fabric, it might not be the right one for you. It may take a few tries before you find a garment that works for you. If you have questions, ask your fitter or your lymphedema therapist. Often, your therapist can speak to the fitter on your behalf.

When to go for a fitting

During the intensive phase of treatment, your lymphedema therapist will record your limb measurements regularly. Once the swelling has been reduced as much as possible, your therapist will advise you to see a garment fitter. Even though your therapist has measured your affected limb(s), the fitter will take separate measurements.

Once in the maintenance phase, you will need to get a new compression garment every 3 to 6 months, depending on how often you are wearing it and the stage of your lymphedema. Your therapist may propose a few decongestive lymphatic therapy (DLT) sessions to reduce the limb as much as possible, before getting measured for the new garment.

How the garment should feel

Your compression garment should be quite comfortable to wear. The fitter will show you how to put it on. Don't

be surprised if it takes a few attempts before you get it right. Make an appointment to see your lymphedema therapist after the first few days of wearing your new garment. It is important to make sure you are wearing the garment correctly, and that it is the right fit for you. A well-fitting garment should go high enough on your affected limb. It should not increase swelling in your affected limb(s) or nearby area(s) (e.g. if you have arm lymphedema and wear a compression sleeve, you should not see increased swelling of your hand on that side). If you experience an increase in swelling, see your garment fitter and lymphedema therapist.



Trying out your new garment

When you order your garment, ask your fitter about its trial or guarantee period. Often, the trial period for a garment will be 7 to 10 days, or more. If you have doubts about the fit or any problems with your new garment, contact your fitter for an appointment as soon as possible. You may just need to change how you are donning the garment, but it could also have been measured or made incorrectly.

A perfect fit is the key to making sure the compression garment is working for you.

Treatment: Lymphatic drainage and self-care education

Taking charge and managing lymphedema is all about finding balance. The goal is to keep your lymphedema swelling and symptoms stable or to reduce them. To do this well, you need to learn as much as you can about lymphedema, to monitor your health, to be aware of what makes your symptoms better or worse and to try your best to manage these elements.

As part of your initial treatment plan, your certified lymphedema therapist will provide you with lymphatic drainage massage and will educate you about taking charge to manage your lymphedema.

Lymphatic drainage is a special type of gentle massage that promotes lymph flow, aids relaxation, reduces pain and helps improve mobility. It is a technique that requires special training and can only be given by a certified lymphedema therapist. The therapist's hands make gentle movements on your skin in a certain direction. This technique helps move lymph fluid from just below the surface of your skin to bigger lymph vessels deep in your body. During the intensive phase of treatment, your lymphedema therapist may do lymphatic drainage before applying compression bandages.

Your therapist may also treat you with other manual techniques to soften hardened (fibrotic) tissue. These techniques can help to treat tissue damaged

by radiation or hardened by tissue swelling.

Self-care education to help you take charge is a very important part of the lymphedema therapist's role.

Lymphedema is a lifelong condition. It cannot be cured, but it can be managed. You will learn how to take charge of your care and what works best for you.

Self-care education for you and people involved in your care includes:

- Good skin care to prevent infection
- Special exercises to help promote lymph flow
- Nutrition advice for a healthy body weight
- Self-measurement, self-massage for lymphatic drainage and compression bandaging techniques for care at home.

Your team

It takes a team to manage lymphedema: you, your family members or close friends, a certified lymphedema therapist, and a family doctor or nurse. You may also benefit from the support of a dietician or nutritionist, a medical exercise or fitness specialist, social workers and other people who care for you. Together, the team will develop a treatment plan that adapts when needed and helps you enjoy life.

Your provincial lymphedema association can connect you with resources.



Treatment: Costs

Most lymphedema therapists in Canada work in private clinics. There are no standard rates that they charge. The cost of one hour of treatment varies greatly, depending on where you live and whether your therapist is a nurse, physiotherapist, occupational therapist or registered massage therapist.

The cost of a compression garment will depend on whether you need a custom-made or ready-made garment. Ready-made (circular knit material) are the least expensive, followed by standard flat knit material and then custom-made flat knit material. A glove made for swelling of the fingers or toes can be more expensive than a compression stocking or sleeve.

Paying for treatment

It's rare in Canada that all lymphedema treatment costs are covered by your provincial or territorial government's health insurance plan. What is covered depends on where you live. This means that people with lymphedema usually have to find other funding sources, use private insurance or pay for treatment. Contact your provincial lymphedema association for advice about funding.

There are a few options to help cover treatment costs:

- **Government health insurance:** Some regional health plans cover compression garments or decongestive lymphatic therapy, while others offer no coverage.
- **Private health insurance:** Workplace health benefits or private health insurance may cover lymphatic drainage under physiotherapy, occupational therapy, massage therapy or nursing care. They may also cover a certain number of compression garments per year, or pay for costs not covered by government health insurance.
- **Income tax deductions:** You can claim some of your treatment costs on your income tax return. For information, visit Canada Revenue Agency (crs-arc.gc.ca, forms and publications).



Community funding

Some groups offer financial help to people on a low income. Contact your local church, Canadian Red Cross, Kiwanis, Lions or Rotary club to see if they offer help.

Reach out for the help you need.

Treatment: Other options

Further research is needed to explore options and develop effective methods to treat lymphedema.

Pneumatic compression

Some hospitals and private clinics may use a pneumatic compression pump to treat lymphedema. The affected limb is put into an inflatable sleeve with many sections, and it remains in the device for one to two hours. Trained staff set the correct level of pressure to reduce swelling and monitor the device. Compression bandaging or a garment must also be used after the pump to control the swelling.

Kinesio taping

A special cotton-weave elastic tape is applied to stretched skin in areas that are difficult to bandage. It can also be used to soften hard areas of the skin by helping to move the fluid in the tissues in stage 2 or 3 lymphedema.

Laser therapy

Some therapists and clinicians may use a low-level laser as part of their overall lymphedema treatment to break down thick, scarred or hardened skin tissue. It can also help increase range of motion and reduce pain for some patients.

Surgery

Lymphedema surgery is not standard treatment yet and is not readily available in Canada. It is used to treat severe

swelling that has not responded to lymphatic drainage or compression therapy. After surgery, the treatment plan must include decongestive lymphatic therapy. For the rest of their life, the person will also need to wear compression bandaging or garments at all times.

Medication

There is no medication to treat or cure lymphedema at this time and research on natural supplements is limited. If you're considering a new supplement, check with a health professional first.



Diuretics and lymphedema

Lymphedema is not the same as water retention. It is treated differently and diuretics are not recommended. However, if you take diuretics for another condition (e.g. high blood pressure, heart disease), keep taking them and speak to a health professional about your options.

Diuretics help rid the body of salt and water but not lymph fluid.

Taking charge of your health

As with any lifelong condition, it is important to learn about lymphedema and how it affects you. Your body and situation are unique. Learn what works best for you. Be patient – adjusting to life with lymphedema takes time and commitment. Having an experienced lymphedema therapist on your side can be a big help.

Treatment and self-care are the foundation of lymphedema care, with the following core elements:

Compression therapy to reduce and control swelling. Use compression bandaging or garments to provide resistance to working muscles and help move fluid and protein out of your affected limb(s). (See pages 10, 11 and 12 for details.)

Good skin care to lower your risk of infection. Keep your skin moisturized to help maintain the skin's natural protective barrier. (See pages 17 and 18 for details.)

Exercise to stimulate your lymphatic system. Exercise regularly at a moderate pace to activate the pumping action of your muscles and joints and promote deep breathing. (See pages 19 and 20 for details.)

Weight control to improve lymph drainage by decreasing the pressure on lymph vessels.

Aim for a healthy body weight to reduce the risk of lymphedema getting worse.

Other things you can do to help manage lymphedema:

- **Take care of other health conditions** – like high blood pressure or a thyroid condition
- **Avoid high temperatures** – stay indoors (ideally with air conditioning) in the high heat and humidity of summer, stay away from hot tubs/saunas, and take warm, rather than hot, baths and showers
- **Avoid tight clothing or jewelry** – or clothing with heavy elastic (e.g. tight sock tops) on the affected limb
- **Practice self-massage** for lymphatic drainage



A healthy body weight helps you manage lymphedema

Being very overweight or obese makes it harder to manage lymphedema. Aim to be more active. Enjoy a balanced diet: lots of fruit, vegetables and whole grains; fewer processed foods and less meat; avoid prepared foods with high sodium level. Drink plenty of water. See *Canada's Food Guide* for tips.

Speak to a health professional for healthy weight-loss ideas.

Taking charge: Skin care

People with lymphedema are at risk for cellulitis and other skin infections because their bodies are less able to fight infection. Bacteria can get into your body through a break in the skin, fungal infections (under nails), an existing wound or another entry point. This is why good skin care is so important.

Good skin care to lower your risk of infection:

- Wash your skin regularly to keep it clean
- Use mild soap, rinse and dry your skin well
- Use an unscented, non-allergenic moisturizer daily
- Disinfect scratches, pinpricks, cuts, burns or splinters and apply antibiotic ointment and Band-Aid
- Use insect repellent; if you get a bite, use an anti-inflammatory lotion/spray to avoid scratching it
- Use sunscreen, reapply often
- Avoid cutting your cuticles, and take care when having a manicure or pedicure to avoid cuts
- Get treated for skin conditions such as inflammations, athlete's foot, dermatitis, fungal infections, ingrown toenails and others
- Use an electric shaver instead of a razor if you need to shave the affected area
- Ask a health professional for an antibiotic prescription for travel outside of Canada

- See a health professional if you have signs of infection

See page 20 for more skin care tips if you have lymphedema of the arm or leg.

What should I do if I have a skin infection?

Cellulitis is a sudden, non-contagious bacterial infection of tissues under the skin. 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.



Watch out for signs of skin infection (cellulitis)

- Rapid onset of skin redness, swelling or pain
- Skin that feels hot or painful to the touch or tingling
- Skin that is red or with a reddish rash or red streaks
- A feeling of tiredness or heaviness
- If cellulitis worsens, you may feel flu-like symptoms, feelings of nausea, fever or chills

Seek medical help right away if you notice any of the above symptoms.

Taking charge: Skin care tips

The following skin care tips are common-sense approaches based on practical experience. The goal is to protect your skin from injury including burns, rashes, chapping, scratches, cuts and punctures. This will lower your risk of infection.

If you have lymphedema of the arm:

- Wear protective gloves when gardening and rubber gloves for household chores
- Wear long oven mitts when using the oven
- If you go for a manicure, let your aesthetician know that you are at risk for infection and that the equipment must be properly sterilized
- Some cancer treatments affect nail growth; if your nails are weak and tear easily, take special care when you cut them
- Use high protection sunscreen and/or wear protective clothing to prevent burning
- Where possible, try to have injections, blood tests or vaccinations in the arm that is not affected
- Wear an alert bracelet during hospital visits to help you communicate your needs to staff

If you have lymphedema of the leg:

- Avoid walking barefoot. Wear beach shoes when you walk on sand, in water (especially if the bottom is uneven or rocky), and when you're in a public shower or change room
- Wear closed, well-fitting footwear and comfortable hosiery or compression garments
- If you go for a pedicure, let your aesthetician know that you are at risk for infection and that the equipment must be properly sterilized
- Get prompt treatment for fungal infections and other foot conditions
- See a podiatrist to have ingrown toenails and other skin conditions treated

Preventing infection

Every episode of infection damages your lymphatic vessels further and makes your lymphedema worse. This leads to a vicious cycle. When lymphedema gets worse, it puts you at greater risk for another bout of cellulitis. With any serious infection, there is also the danger of bacteria entering the bloodstream and making a person critically ill.

Practicing good skin care helps prevent infection.



Taking charge: Exercise

Being active offers so much to our health and wellness, and you should not avoid it because of lymphedema or cancer treatment. It can also reduce the risk of cancer recurrence and is beneficial for lymphedema. Depending on your health and fitness level, different types of exercise may be appropriate at different times. Regular exercise is a key part of your lymphedema self-care. By moving your muscles and breathing more deeply, you stimulate your lymphatic system and help your lymph flow.

The benefits of regular exercise include:

- Improved blood and lymphatic circulation
- Improved muscle strength, so you feel stronger
- Better joint mobility
- Increased fitness and less injury
- Helping to get to or maintain a healthy body weight
- Overall mental and physical wellness

During the intensive phase of treatment to reduce swelling, your certified lymphedema therapist will show you special exercises. Your therapist will also encourage you to be active during the maintenance phase.

Being active includes many things:

- Organized sporting activities
- Working out at a gym or in your home
- A brisk walk with friends or to do errands
- Running around with your children or grandchildren
- Work about your house or garden

Exercise safely. Seek advice from your self-care team: your family doctor or nurse, lymphedema therapist, and medical exercise or fitness specialist.



Educating your trainer

Be aware that many fitness specialists or personal trainers may not have heard of lymphedema or know anything about it. You'll need to educate them about the condition, what helps you and what you need to avoid. You can also refer them to your lymphedema therapist for information about the benefits and risks of exercise to help you manage your lymphedema.

Educating others about lymphedema may help to improve your condition.

Taking charge: Guidelines for being active

Before starting any new activity, let your instructors know that you have lymphedema. Refer them to your lymphedema therapist for more information.

Tips for getting started

- Measure your affected area before starting a new activity
- Wear a well-fitting compression garment while you exercise
- Start slowly (for a short time with low repetitions and low weights)
- Progress at your own pace, build your strength and stamina slowly, and don't overdo it
- Get advice on equipment use, body posture and positioning to prevent injury
- Make time for deep breathing and water breaks to stay hydrated
- Pay attention to any pain or discomfort during/after exercise and modify as needed
- Monitor for changes in swelling and keep a record of measurements

Types of activity

Your lymphedema therapist can advise you about safe exercise and different ways to be active, including the benefits of:

- Pool exercises like aqua fit, aqua lymphatic therapy or

just walking in water (water pressure acts like a natural compression garment)

- Walking, gentle cycling, dancing and light aerobics
- Gentle stretching and rest after cardiovascular exercise or strength training
- Yoga and Pilates; however, if you have upper body lymphedema, ask your instructor for alternatives to poses that require static weight-bearing of the arms (e.g. downward dog)
- Changing activities to avoid overusing one area (e.g. vacuum one room rather than the whole house in one go)



What works for you?

The key is finding activities that fit into your life and that you enjoy. Avoid sudden activities that your body is not used to, such as joining a gym and overdoing it on the first day or moving a lot of furniture in your home over a short time. Easy does it!

Regular exercise is easier if you choose an activity you enjoy.

Taking charge: Making self-care part of every day

Taking charge of lymphedema takes time, patience and commitment. You will need to alter your daily routine at work, at home and during leisure activities.

At work

You may wish to make your employer aware of your health condition and how it affects you. If your job involves long periods of standing or sitting, this may be an issue for you. Lymphatic drainage is helped when you move and change positions at regular intervals. You can build this into your work day by setting an alarm on a computer or phone to remind yourself to change position and move regularly. If intensive therapy, stress or other issues impede your return to work or your performance on the job, speak to your family doctor and/or lymphedema therapist for advice.

At home

You may find it helpful to involve your partner or older children in your self-care. They could help you apply bandages or don compression garments. For this reason, you may wish to have a family member with you when you visit your lymphedema therapist. It can also be a big help to let family members or friends take on some of your tasks and responsibilities, especially the more physical ones around the house, in a garden,

or grocery shopping. You may also want to seek help from community services. Or perhaps you prefer to be as independent as possible. Let your therapist know what your goals are, so s/he can help you make lifestyle changes that work for you.

Find the moments that are most convenient for your self-care. Some people spend more time in the shower, to do self-massage or stretching exercises while the warmth loosens their muscles. Others will do their self-massage while watching TV. When you get dressed or undressed may be the perfect time to apply moisturizing cream and protect your skin. You may find it easier to divide your self-care into small steps throughout the day, or you might prefer to do everything at once. There is no one single way to manage your lymphedema.

Intimate relationships

If you have a partner, lymphedema and its therapy may affect your emotional and sexual life as a couple. It may be helpful to discuss your concerns with your partner, as well as your lymphedema therapist, family doctor or another health care professional.

Reach out to find the support that you need.



Where can I go for support?

Lymphedema can impact your home, work and social life. Know when to ask for help. You may wish to get psychosocial support to help enhance your coping skills. Consider involving your family and friends in the self-care and educational aspects of your therapy.

Try to make time for healthy lifestyle choices, such as getting enough rest, doing leisure activities you enjoy, exercising, seeing supportive friends and family, and creating space for reflection and relaxation.

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 eight regional associations that support people living with lymphedema. Contact your provincial 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 23).

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

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.



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

Nova Scotia: Lymphedema Nova Scotia
www.lymphedemanovascotia.com

Ontario: Lymphedema Association of Ontario
www.lymphontario.ca

Quebec: Lymphedema Association of Quebec
www.infoympho.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

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

Let's Talk Lymphoedema
By Peter Mortimer and Gemma Levine

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 French resources including information on books, publications, support groups, clinical resources and a selection of Pathways French translated articles, visit the Lymphedema Association of Quebec website:

www.infoympho.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



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Canada's national lymphedema magazine, empowering patients and professionals



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