



# *Lymphedema*



What  
Breast Cancer Patients  
Need to Know



The information in this booklet focuses on secondary lymphedema from breast cancer treatment. Secondary lymphedema can also happen after surgery and treatment for other types of cancer. Secondary lymphedema may affect the leg, arm, breast, trunk, abdomen, neck, head, and or genitals. Some of the information in this booklet can be helpful if you have lymphedema from other causes. However, it is important to discuss your condition with your health care provider.



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## Introduction:

This booklet was developed by the Thunder Bay Regional Health Sciences Centre, Regional Cancer Care, with funding from the Northern Cancer Research Foundation. The goal of this booklet is to raise awareness of lymphedema and educate women and health care providers about the risks, symptoms, prevention and treatment of lymphedema.

This booklet provides information that will:

- Talk about lymphedema as a possible side effect of cancer treatment.
- Teach you about the signs and symptoms of lymphedema and when you might be at risk for getting it.
- Help you make choices about your care.
- Tell you about treatments for lymphedema in Northwestern Ontario.
- Tell you where you can get help in Northwestern Ontario.

## 1. Lymphedema and the Lymphatic System

### a. What is Lymphedema?

(Pronounced: lim-fa-deem-a)

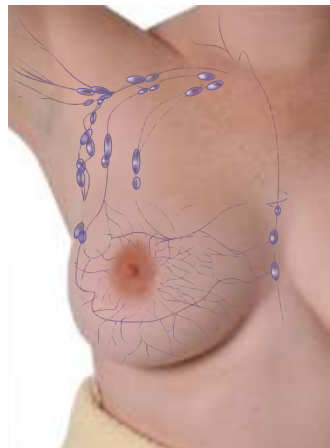
Lymphedema is the unusual or abnormal swelling of a body part. The swelling is caused by lymphatic fluid building up in body tissue. This swelling happens when the lymphatic system is damaged. Lymphedema can be treated, but not cured. It can be a serious problem if it is not treated. Lymphedema can be controlled with the right treatment and care.



Lymphedema present in arm on right

### b. How does the lymphatic system work?

The lymphatic system carries lymph fluid away from body tissues. It drains away extra fluids and protein so that tissues do not swell. It also helps fluids and nutrients move around the body.



Lymph nodes and vessels



c. What are the most common causes of lymphedema?

Lymphedema can occur when the nodes and lymphatic vessels are damaged or taken out during surgery. It can also be caused by:

- radiation used during cancer treatment
- trauma or injury
- infection
- malignant tumours
- immobility

When lymphatic tissues or lymph nodes have been damaged or removed, lymph fluid cannot drain normally from that area. The area can become swollen and heavy with fluid.

d. How often does lymphedema occur?

One of five women with breast cancer will have mild to severe lymphedema during their life. Most lymphedema related to breast cancer happens in the first three years after surgery with Axillary Node Dissection. Patients who are treated with both radiation and chemotherapy are three times more likely to have lymphedema than those who only have chemotherapy.

*Axillary Node Dissection:  
Lymph nodes under the arm  
are removed during surgery.*

e. Can lymphedema be prevented?

Lymphedema cannot be completely prevented. If symptoms are found and treated early, it can be controlled and managed. The only risks that can be controlled are infection and injuries to the arm. If you have questions or concerns about your surgery and lymphedema, discuss your options with your surgeon.





## 2. Are You At Risk?

### a. Lymphedema risk factors

Most women who have surgery for breast cancer also have some underarm lymph nodes removed. This is called **Axillary Node Dissection**. Sometimes removing lymph nodes and radiation treatments can damage the lymphatic vessels, nodes and tissues in the underarm. This damage can cause a blockage. A blockage slows the circulation and drainage of lymphatic fluid. More fluid comes into the arm than can leave. The fluid builds up, stays in the arm tissues and causes swelling.

If you have had breast cancer treatment that included surgery to take out lymph nodes, radiation or chemotherapy, you have higher risk of getting lymphedema. The following can increase your risk even more:

- Do you have scars from injuries, burns, surgery, or radiation?
- Is there a history of swollen feet or legs in your family?
- Is there a history of heart or circulatory problems in your family?
- Are you overweight?
- Do you have diabetes?
- Are you a smoker?
- Have you had previous surgeries under the arm?



Mild/Moderate lymphedema present in the arm on the right.



Severe lymphedema before treatment



Severe lymphedema after treatment



b. What breast cancer patients need to know

Lymphedema can occur soon after breast cancer treatment or years later. An injury to the arm can cause lymphedema even years after being treated for breast cancer. Injury or infection can cause lymphedema or make it worse.

Lymphedema can also be caused by cancer growing in the lymph glands or tissues near the original cancer site. If the lymphatic systems were not damaged by surgery or radiation treatments, lymphedema may never happen. It is hard to say who will get lymphedema.

### 3. Early Warning Signs and Symptoms of Lymphedema

Lymphedema can happen right after surgery or radiation therapy. It can also happen years later, without warning. The symptoms of lymphedema usually show in the arm nearest the surgery or radiation site. These symptoms include:

- **Swelling/puffiness** of the arm, hand, chest or shoulder on the same side as the surgery. This may happen gradually or suddenly.
- **The arm gets larger.** This may happen gradually or suddenly.
- **Tightness** of the skin, and a feeling of heaviness in the area.
- **Discomfort** or a “pins and needles” feeling in area.
- **Indenting** of the skin when swollen area is pressed.
- **Aching or heavy** feeling of the limb.
- **Redness** or other signs of an infection in the area.
- **Feeling of warmth** of the arm or body part with no redness.
- **Bursting or shooting pain** that happens off and on in the affected area.

#### **Pay Attention to Your Body**

Know and watch for the early warning signs of lymphedema. They are as simple as:

- feeling of heaviness
- your ring or watch becomes too tight

If you have any of these symptoms, **do not wait. Call your doctor or therapist right away.** Being treated early is better and can improve your health and lifestyle.





## 4. Prevention

If you have had treatment for breast cancer, you can get lymphedema at any time. But, the risk can be lowered.

Prevention Steps:

1. Protect your skin - it is important to take very good care of your skin.
2. Watch for infection - see your doctor as soon as you notice any signs of infection. These include: redness, pain, heat, swelling of the arm, fever.
3. Slowly work at getting back the same ability to move your shoulder as you had before cancer treatment.
4. Slowly get back to being as active as you were before cancer treatment.

Exercises to help lymph fluid drain and help prevent lymphedema:

Start exercising slowly and little-by-little increase how much you can do. If you begin to feel pain, do less. Do the exercises until you see your surgeon for your follow-up visit. If you have any questions or problems, check with your doctor. If your problems are serious, go to the nearest hospital and contact your doctor.

a. The first days after surgery:

Lift your arm and do some gentle exercises to help lymph fluid flow. Repeat each exercise as you feel comfortable.

For example:

1. Lie down and put a pillow under your arm. Gently squeeze a ball or squeeze your fist.



2. Clasp your hands together or hold the ends of a short stick and gently raise your arms as high as is comfortable.





### 3. Deep breathing exercises help increase the lymph flow



b. When you get home:

Doing these exercises regularly can improve lymph drainage in the arm. Talk to your doctor or therapist about starting the following exercises:



1. Pendulum exercise: Stand with your feet apart and bend forward. Rest your unaffected arm on a table or back of a chair. Let your affected arm hang down loosely from your shoulder and gently swing your arm from side to side, back and front. Then make small circles, slowly getting bigger as your arm relaxes.



2. Wall climbing: Stand with your feet slightly apart and 6 to 8 inches away from the wall. Starting from shoulder level, little by little try to walk your fingers higher up the wall. Repeat. Mark how high you reach each day. Sometimes it may be hard to reach the mark you made the day before. Do not worry, just try again later in the day.

3. Arm pulley: Using a pulley, hold the lower cord in the hand on the side of your surgery and the higher cord with your other hand. Gently pull the higher hand down and raise the lower arm. Repeat, little by little raising your arm higher each time.



4. Hand squeezing exercise: Put a small rubber ball in the palm of your hand. Squeeze gently then relax.

5. Forward head roll: Bring your chin forward toward your chest and slowly turn your chin from side to side.

Do not start any exercise program without first talking with your doctor or therapist. **DO NOT FORCE YOURSELF WHEN YOU ARE DOING ANY EXERCISE.** If you have any swelling or feel any tightness in your scar tissue, talk with your doctor or therapist right away.

c. Preventing lymphedema - DOs and DON'Ts

Sometimes it is not possible to prevent getting lymphedema. But, you can lower your risk, have less severe symptoms and avoid infections by following these tips. Because you can get lymphedema years after being treated for breast cancer, you should always do the following:

DOs and DON'Ts to reduce lymphedema risk

### Outdoors



**DO** protect your arm from the sun. When outdoors wear a sunscreen with SPF 15+. Reapply often, at least every two hours and after swimming.

**DO** wear gloves when gardening, doing yard work or any where you can get even a small injury.



**DO** talk with your therapist before starting an exercise program. Do not overtire an arm at risk. If your arm starts to ache, lie down and keep it up on a pillow.

**DO** get regular exercise, but do not repeat the same exercise to the point that your muscles feel tired. (Such as: scrubbing or pushing or pulling against the arm).



**DO NOT** allow pets to scratch or bite your hand or arm.

**DO NOT** put your arm in extreme heat such as hot tubs, whirlpools or saunas.

**DO NOT** play sports which can hurt your arm or hand.

**TRY NOT** to get insect bites. Wear insect repellent, long sleeves and long pants.



### Indoors



**DO** wear gloves while doing housework.



**DO** wear oven mitts when moving hot plates to and from the oven or burner.

**DO** avoid burns from grease splatter when cooking.

**DO** keep your arm up when you can. Sleep with your arm propped on pillows so it is higher than your body.



**DO NOT** sew unless wearing a thimble to protect against finger pricks.

**DO NOT** wash dishes in extremely hot water with bare hands. Use rubber gloves.



### Hygiene

**DO** keep your arm very clean and use a moisturizing cream without perfumes.

**DO** clean any scratch or cut right away and use an over-the-counter antibiotic cream.



**DO** dry your arm very well after bathing, but **DO NOT** rub the arm harshly with your towel.



**DO** self-massage on your arm every day as instructed by your therapist.

**DO** call your doctor right away if you see any sign of infection. (redness, pain, heat, swelling of the arm, fever)

### Grooming and Accessories

**DO** wear a well-fitted soft bra with padded shoulder straps that is not too tight. Women with large breasts should wear light breast prostheses (heavy prostheses may put too much pressure on the lymph nodes above the collar bone).

**DO** use an electric razor

**DO NOT** wear tight jewelry or watches on the arm or hand of your affected side.

**DO NOT** carry a heavy purse, bag, or briefcase over the shoulder of an at-risk arm.

**DO NOT** bathe in very hot water. Avoid saunas and hot tubs (or keep the affected arm out of the hot tub)

### Travel

**DO** wear a compression sleeve or bandage anytime you fly. This helps your body with the pressure changes in the plane's cabin.

*Compression garments are two-way stretch sleeves that aid in controlling swelling. See page 15*



**DO** rest your arm on a nest of pillows. This is easier to do if you sit with your affected arm near the window.

**DO** drink more fluids while flying.



**DO** remember to pack soap, moisturizer, antibiotic cream or ointment, and bandages to care for your arm.



**DO NOT** lift or carry heavy bags with your affected arm. Do not carry handbags or bags with shoulder straps on your affected side.

**DO NOT** drink alcohol when flying.



### Medical



**DO** wash cuts right away. Treat with antibacterial medication and cover with a sterile bandage. Check often for redness, soreness or other signs of infection

**DO** wear a well-fitted compression sleeve during the day while you are awake if your therapist has told you to do so. If the sleeve is too loose, your arm has become smaller, or you need a new sleeve. Check with your therapist to get fitted for a new one.

**DO** keep your ideal weight by eating a well-balanced, low sodium, high-fiber diet.



**DO** wear a medic alert bracelet on the affected arm that says "no injections, blood pressure, etc."



**DO** talk with your doctor or therapist about what to do if both arms are affected.

**DO NOT** allow blood to be taken from an at-risk arm.

**DO NOT** allow vaccines or other shots to be given in an at-risk arm.

**DO NOT** allow a blood pressure cuff to be used on an at-risk arm.

**DO** insist that medical personnel use the other arm or another appropriate site.

**DO NOT** allow acupuncture in the affected area.

**DO NOT** limit protein in your diet. Lymphedema is a high protein edema (swelling); but eating too little protein will not lower the protein in the lymph fluid. Not eating enough protein can make it worse.



**DO NOT** smoke and if you drink alcohol (wine, beer, liquor) use wisely. Do not drink too much.



Finally,

**DO** seek medical attention right away if you have any signs of infection like fever, redness, pain, heat or swelling in the arm.

## 5. How Does the Doctor Know I Have Lymphedema

There are no specific tests for diagnosing lymphedema at this time. Computerized Tomography (CT Scan) and Magnetic Resonance Imaging (MRI) have limited value for diagnosing lymphedema.

About half of patients with mild swelling (edema) describe their affected arm or leg as feeling heavier or fuller than usual.

To rule out other conditions which may have similar symptoms, your health care provider will complete a medical history and physical examination. The medical history will list

- past surgeries
- problems after surgery
- the amount of time between surgery and the start of the swelling
- changes in the swelling
- any injury or infection
- any medications you are taking

## 6. Treatment

If you do develop lymphedema, there are ways to help decrease it.

Lymphedema treatment methods

The most effective treatment for lymphedema is known as Combined Decongestive Therapy (CDT). CDT includes: Manual Lymph Drainage (MLD), Compression Therapy, Decongestive Exercises, Skin Care and teaching patients how to take care of themselves in a new way. The goals of these treatments are to:

- **Move lymph fluid out of the tissues**
- **Reduce swelling**
- **Control swelling**
- **Soften toughened skin (fibrosis)**
- **Improve the patient's general health**



a. Manual lymph drainage: often called **M-L-D**, is a gentle manual treatment that was developed in 1932 by Dr. Vodder. This technique has been widely used in Europe and is now accepted throughout the United States and Canada. Manual lymph drainage helps lymph fluid find new ways to flow around blocked areas into healthier lymph vessels.

MLD treatment is a special type of massage that uses light strokes that are done in a certain pattern along the lymphatic vessels and tissues around them.

The butterfly symbol of lymphedema is based on this technique that is said to be, "*as gentle as a butterfly kiss.*" These movements help to reduce swelling and return lymph to the circulatory system.

Not all therapists are certified to work with lymphedema patients. Make sure you ask your therapist if they are a Certified Therapist trained to do MLD for lymphedema.



Therapist performing MLD on a lymphedema patient

b. Compression: an important way of controlling swelling using bandages or compression garments on the swollen area of your body.

Compression is used to:

- Keep the progress made from the MLD treatment.
- Help natural drainage by supporting the tissues.
- Prevent any more swelling.
- Help to soften **fibrotic tissue**.

The types of compression used for lymphedema treatment are:

a. Bandages

Bandages, also known as short stretch bandages, are used to replace skin pressure lost from lymphedema.

They also stop lymph fluid from building up after it has been cleared by Manual Lymph Drainage (MLD).





## When is bandaging used?

Not all lymphedema patients need bandaging. Your therapist might use bandages in your early treatment. A bandage needs to be put on evenly, with more pressure at the hand and less pressure as you bandage up towards the shoulder. Putting on the bandage the right way is very important to move the fluid in the right direction. Pockets of pressure from an uneven bandage can cause pockets of swelling. A trained therapist is the best person to teach you how to bandage.

### Bandaging basics

Learn and follow the bandaging method recommended by your therapist. Every detail is important, so pay close attention. If you have questions, ask for written or video instructions. It may be helpful to have a family member learn how to do the bandaging. You may need help in applying the bandages properly.

**DO** reuse bandages. Keep them clean so that they will not lose their stretch and be easier to put on.

**DO** follow the manufacturer's instructions for washing bandages, so they keep their shape and stretch. It is best to have two sets of bandages: one to wear and one to wash.

**DO** remain active when you are wearing bandages. They should not prevent normal daily activity.

**DO** talk to your therapist about bandaging techniques.



Therapist applying bandages to hand and arm of lymphedema patient

### b. Compression garments

Compression garments are elastic sleeves or stockings that keep swelling down by providing support.

*Compression garments only work when you wear them regularly. Your therapist will decide if you need compression garments.* Before buying, check with your therapist.



It is not a good idea to walk into a medical supply store and ask for a sleeve. If the garments do not fit properly, they can cause you more problems. Your lymphedema therapist or a trained fitter will measure you and tell you which garment is best for you.



Compression sleeve and glove

You will need a doctor's prescription for a compression garment. Your lymphedema therapist and doctor will decide how much compression you need. You may be fitted with a ready-made garment or a custom-made garment. Custom-made garments cost more and take longer to make.

Compression garments only work when they are worn regularly. You wear compression garments while you are awake. They fit well under clothing.

**DO** wear your compression garment all day, including during exercise. Usually, they are not worn at night while sleeping. Your therapist will tell you if you need to wear a compression garment or bandage at night.

**DO** have your compression garment checked by your therapist every six months to make sure it fits. The size of your affected limb will change. A compression garment only works well when it fits well. Your compression garment will lose some of its stretch and then it will not work well. You might need to replace your compression garment about every six months.

**DO** try to have two compression garments. You can then wear one while the other is being hand-washed.

**DO** call your insurance company or the Assistive Devices Program (ADP) to see if they will help pay for the garments. (See page 26)



Rubber gloves help you to get your sleeve on and protect it from punctures or tears



c. Decongestive exercises: help the flow of lymph and over time, decrease swelling.

You will get a written list of decongestive exercises or a video from your lymphedema therapist based on your own needs.

Should I wear my compression garment/bandages when doing decongestive exercises?

Yes, always do your decongestive exercises wearing your compression bandage or garment. This helps to better use the muscle and joint pumps in your arm. It also helps to move lymph fluid and soften toughened skin (fibrosis).



Decongestive exercise wearing bandages



How often should I do decongestive exercises?

You should do decongestive exercises 2 times a day for about 10 to 15 minutes each time. Do not do more than this. Do the exercises slowly and relax between each exercise. Use the proper breathing while you exercise. This will help the lymphatic system. After you exercise, rest and raise your arm for about 10 to 15 minutes.

Decongestive exercise wearing compression garment

## 7. Self Care

a. Self Massage: a massage you do yourself between lymphedema treatments.

Self-massage is important in treating your lymphedema. Self-massage is a form of Manual Lymph Drainage (MLD). It is best to do these gentle movements at a time and place where you are relaxed and will not be disturbed.



Lymphedema patient performing self massage



Your lymphedema therapist should teach you how to do the self-massage movements that work best for your condition. It is important that you follow these instructions and do your massage regularly. Ask your lymphedema therapist for written instructions.

**Caution: Self-massage movements are not the same for all lymphedema patients. Make sure your lymphedema therapist teaches you the movements that are best for you.**

## b. Skin and nail care

### Introduction

Keeping your skin healthy is very important. Skin with no scrapes or cuts keeps bacteria from getting in and infecting the tissues. The swelling of lymphedema stretches the skin and prevents the skin from protecting the tissue. Also if lymphedema gets worse, the skin does not stretch as well, becomes thicker and scaly, and can get infected more easily.

### Skin care steps

**DO** use only mild soap.

**DO** wash gently and well with warm (not hot) water.

**DO** dry gently by patting. Make sure you dry within the skin folds.

**DO** keep the skin moisturized using a low PH lotion. This helps keep the skin elastic to prevent cracks/breaks. Your therapist can recommend a brand of skin cream.

**DO** check your skin each day to look for any possible cracks or signs of infection.

**DO** protect yourself from sunburn. Skin that has been affected by lymphedema is very sensitive to the sun. A compression garment does not protect it from the ultraviolet (UV) rays. Wear protective clothing when in the sun.

### Nail care

Taking care of your nails is important, because any break in the skin around the nails can become infected. Follow these steps to take care of the nails on any limb affected by, or at risk of lymphedema:



**DO** keep your fingernails trimmed short and straight across. This helps stop scratches.

**DO** tell your manicurist or pedicurist that you have lymphedema. They need to be very careful that you do not get an infection. Make sure that everything is clean and that the equipment is sanitized.

**DO NOT** allow your cuticles to be cut. They can be cut too close, making it easy for bacteria to get in and cause an infection.

**DO NOT** use an acetone nail polish remover. The acetone in nail polish removers is a chemical that can enter the skin. Use a non-acetone nail polish remover and do not get it on your skin.



**DO NOT** put on fake nails. They can cause fungal infections.



### c. Nutrition

There is no special diet that will prevent or control lymphedema, but eating well makes you healthier. If you have a condition like heart disease or diabetes, keep the diet you have now. Make sure you talk to your doctor before starting any new diet.



### What about protein?

Since lymphedema fluid contains a lot of protein, many people ask:

*“Should I stop eating protein so there will not be protein in my lymphedema fluid?”*

The answer to this question is:

*“Keep eating protein. Not eating protein will not make your lymphedema better.”*



## Eating a balanced diet

To stay healthy, keep your weight down. Eat a well-balanced diet that includes vegetables and fruits. Healthy eating also helps your body cope with the added stress of having lymphedema. Do not eat foods with lots of salt. Salt can add to swelling by making your body retain fluid.



## Maintaining normal weight



Staying at the best weight for your height and age is a good way to manage your lymphedema. Losing extra weight can help control lymphedema. Some studies say that obesity (being very overweight) increases your risk of getting lymphedema.

If you have any questions about healthy eating and managing your weight, ask your doctor. Your doctor can refer you to a dietician if you need help with learning what to eat.

## Keep hydrated

To keep hydrated, drink lots of fluid, mostly water. Cutting back on fluids to reduce the swelling of lymphedema does not work. Instead, the protein-rich lymph of lymphedema attracts more fluid from the other parts of the body. This can cause more swelling.

Hydrated means having enough fluids in the body to remove impurities from the blood. It is important to good health.

Drinking lots of water is very important after an MLD lymphedema treatment. Water will help flush out the impurities that were moved during treatment. Talk with your doctor or therapist about how much water you need to drink.



Caffeine lowers the fluid levels in your body by making the kidneys put out more urine. You should only eat or drink things that have caffeine once in a while. (Coffee, tea, chocolate and many soft drinks contain caffeine)



Alcohol (beer, wine and liquor) has the same effect as coffee. It can also make you dehydrated. Talk with your doctor or therapist about alcohol and whether or not you should drink alcohol during treatment.

## 8. Complications of Lymphedema

### a. Fibrosis

In the early stages of lymphedema, the tissues swell and do not drain properly. The area is soft to the touch. Pressure leaves an indent that takes time to fill back in.

Fibrosis: The term fibrosis means hardening of body tissues.

If the lymphedema is not treated at this stage, the tissues can get hard (fibrosis). Fibrosis can occur even in tissues with only some swelling.



Fibrosis in the forearm

### b. Infections and wound healing

Wounds can happen in day-to-day living. For example:

- scratches from gardening
- burns from cooking
- a nail infection or wound from a manicure or pedicure
- an insect bite

A limb with lymphedema is at high risk of infection. If a wound is not treated quickly, an infection can spread and cause much swelling.

If an infection is not treated, it can get into the bloodstream and involve the rest of your body. Get medical treatment right away if you have any of these signs of infection:

- redness
- pain
- heat
- swelling in the arm
- fever

### c. Pain

Lymphedema can feel uncomfortable but does not usually hurt. If it is not treated, it always gets worse. It can then lead to pain.





## Managing pain

According to the National Cancer Institute, the most successful treatment for the pain from lymphedema is to decrease the lymphedema. Once the swelling goes down most of the pain should go away. But you should always tell your therapist about any other pain you have.

## 9. Exercise

### a. How exercise helps lymph flow

Moving muscles and skin during exercise helps drain lymph out of the area and back into the bloodstream. Lymph flow moves 15 times faster during exercise. That is why an exercise program is an important part of the treatment and management of lymphedema. Exercise also gives you more energy and helps you feel better. Your therapist should tell you how to do exercises that are right for you.

Deep breathing and gentle hand squeezing exercises help increase lymph flow.



Stretching and flexibility exercises help to loosen scar tissue and keep your joints and muscles moving so they feel less stiff and painful. Loosened areas move better and are less likely to get strained or injured. Scar tissue can tighten for up to 18 months after surgery and for 6 months after radiation therapy. Stretch regularly to keep your chest wall and armpit flexible.



### b. Exercise precautions

Before starting any exercise program, talk to your therapist or doctor.

- **Do not over-do it** and do not over-use your affected limb.
- **Start slowly** and carefully. Follow the “warm up” and “cool down” steps of your exercise program.
- **Wear your compression garment or bandage** during exercise. If you have questions about this, ask your therapist.
- **Do not get overheated** and be sure to drink plenty of water to keep your body hydrated.
- **Stop exercising** right away and raise your arm if you have more swelling, tightness or pain. If these symptoms do not go away, talk to your therapist or doctor right away. Check with your therapist or doctor before restarting your exercise program.



c. Types of Exercise

This chart provides some general information about the benefits and /or concerns of exercises.

Types of Exercises	PROS	CONS
Stretching: Yoga Pilates Tai Chi Qi Gong	Relieves tightness, increases range of motion, flexibility, and freedom of movement, increases the flow in the lymphatic channels.	Stretching alone does not improve endurance or strength. <b>Consult your therapist</b>
Low Impact Aerobics: Walking Biking Hiking Swimming Calisthenics  High Impact Aerobics: Exercises where both feet leave the floor and there is jarring of joints Running Jumping Jogging	Improve blood & lymph circulation. Help flow fluid away from affected areas. Combat fatigue. Increases sense of well-being.	High impact aerobics are not usually recommended for those with lymphedema. <b>Consult your therapist</b>
Weight Training: Resistance from dumbbells weight machines other weight training devices to stress and build the muscles	Exercises with light weights (one- or two-pound) may be helpful	Weight training involving the affected limb is not usually recommended for those with lymphedema. <b>Do not lift more than 15 pounds.</b> <b>Consult your therapist</b>
Strength Training: Also known as resistance training requiring muscles to exert force against some sort of resistance	Helps to move lymphatic fluid away from the affected area. Encourages deep breathing. Stimulates lymphatic drainage	Commonly performed with light weights or stretch bands. The use of heavier weights is usually not recommended. <b>Consult your therapist</b>
Water Sports: Swimming Aquatics Aqua-Lymphatic Therapy	Swimming is an ideal exercise because it combines muscle action on the inside with the additional benefit of water pressure on the outside of the arm.	Breast stroke and butterfly stroke are not usually recommended. <b>Consult your therapist</b>
Other Recreational Activities: Baseball Basketball Bowling Canoeing/Kayaking Curling Golfing Racket ball Rowing Skiing - Downhill Skiing - Cross country Tennis		May increase edema. Not usually recommended for those with lymphedema. Vigorous repetitive motion with your arm to the point of muscle fatigue is not recommended for lymphedema patients. <b>Consult your therapist</b>



Always check with your doctor or lymphedema therapist before starting any new exercise program.

Remember that any exercise or activity that you do over and over can cause extra fluid to build up in the tissue. Even doing something light, but in a repetitive way, like cleaning a table, wiping a window, or working at the computer for a long time, can make the muscles in your arm tired and can cause more swelling.



Exercise moderately and do not overuse your affected limb.



## 10. The Emotional Side of Lymphedema

### a. Your emotional health

Lymphedema can change how you see yourself. It can also change your daily routine and what clothes you can wear. It can be a constant reminder of your breast cancer. You may feel pain or discomfort. Your arm may look swollen and unattractive. You might also be distressed by the extra care and cost of the problem.

People have different feelings about having lymphedema, and all of them are normal. You might be angry that you were not warned about getting lymphedema. Or you might feel angry or depressed because you will need to cope with lymphedema for the rest of your life.

Treatment can take a lot of time, effort and money, which can make some people feel frustrated. Some people feel depressed or helpless.





It is important to talk about your feelings with friends, family, and health professionals. It can help to know that you have choices about how to manage your lymphedema. A lymphedema therapist can explain your treatment options and help you decide which is best for you. It takes a lot of patience, and trial and error.



#### b. Where to get help

Supportive Care Services at Regional Cancer Care has free confidential counselling and supportive care services to cancer patients and their families. Individual counselling is provided for the stress, anxiety, and depression that can happen when you are told you have cancer. Individuals, couples, and families can get help any time. Supportive Care staff can also help you with looking for drug coverage, or making travel plans for treatment outside of Thunder Bay.

You can make an appointment to speak with one of the social workers, chaplain, or psychologist at the centre. Your family doctor can refer you, or you can call yourself. You can get counselling any time after you find out you have cancer, while you are being treated, or years after your treatment.

Sometimes people just want to talk on the phone for a few minutes to see if the services that are available will help them. You can always call and leave a message. A staff member will call you back and talk with you over the phone. Then if you want, you can make an appointment.

Supportive Care Services is located on the third floor of the Regional Cancer Care.

Phone 1-807-684-7200 or  
Toll Free: 1-877-696-7223



Remember that it is important that you still do things that you enjoy. You may need to change some ways of doing things so they do not cause extra swelling. Talk with your therapists for help with this.

See the insert at the back of this booklet for local resources that are available in Northwestern Ontario.



## 11. The Cost of Lymphedema

Lymphedema patients can become worried about paying for lymphedema treatment. People who are on fixed incomes or do not have health insurance might not have enough money to cover the costs. Some women may choose less costly treatment or not get any follow-up care.

Contact your private insurance company to see if they will pay for physiotherapy treatments and/or lymphedema garments, or contact Thunder Bay Regional Health Sciences Centre, Regional Cancer Care at: 807-684-7200 or Toll Free: 1-877-696-7223.

Ontario's Assistive Devices Program (ADP)

ADP: Pressure Modification Devices

Part of the cost of Compression garments for chronic lymphedema are covered through the Assistive Devices Program (ADP).

You can apply for ADP if you:

- are a resident of Ontario
- have a valid Health Card
- need a garment or device for at least six months of regular daily use.

What you should do first:

Contact a Registered ADP authorizer for Lymphedema compression garments or a vendor registered by ADP. Or call ADP at:

Toll Free: 1-800-268-1154

Toll Free TDD/TTY: 1-800-387-5559

See the insert in the back pocket of this booklet.

Your first garment might not be your last:

Your compression garment needs to be checked by your therapist every six months to see if it still fits. The compression garment works well only when it fits well, and your arm will change size during treatment. Also, your compression garment will lose some of its stretch over time, so you will need a new one about every six months.

It is a good idea to have two compression garments. That way you can wear one while the other is being hand washed.





**Remember:** A certified lymphedema therapist should assess you for compression garments. It is not a good idea to walk into a medical supply store and ask for a sleeve. If the garments do not fit properly, this can cause problems. Your lymphedema therapist or a trained fitter should measure you and tell you which garment is best for you.



## 12. For More Information

### a. Websites

The Canadian Lymphedema Foundation: An organization established in spring 2002 to promote and support lymphatic research in Canada.

[www.lymphedema.ca](http://www.lymphedema.ca)

Lymphovenous Canada: This website links people in Canada with dysfunctioning lymphatic systems with health care professionals and support groups in their communities and around the world. Also lists latest developments in scientific research and treatment.

[www.lymphovenous-canada.ca](http://www.lymphovenous-canada.ca)

Lymphnotes: An online information resource and support group for those with lymphedema and for the family, friends, and therapists who care for them.

[www.lymphnotes.com](http://www.lymphnotes.com)

The National Lymphedema Network (NLN): An internationally recognized non-profit organization providing education and guidance to lymphedema patients, health care professionals and the public by providing information on preventing and managing lymphedema.

[www.lymphnet.org](http://www.lymphnet.org)

Dr. Vodder School North America: Provides highest quality education in the Dr. Vodder method of Manual Lymph Drainage and Combined Decongestive Therapy. Lists the name of certified therapists by area.

[www.vodderschool.com](http://www.vodderschool.com)



National Cancer Institute: This patient summary is adapted from the summary on lymphedema written by cancer experts for health professionals.

<http://www.nci.nih.gov/cancertopics/pdq/supportivecare/lymphedema/patient>

The Lymphedema Association of Australia, Inc.: This website contains a summary of information about lymphoedema, its causes and treatment, and related matters, together with essential reference material.

[www.lymphoedema.org.au](http://www.lymphoedema.org.au)

Lymphatic Research Foundation

[www.lymphaticresearch.com](http://www.lymphaticresearch.com)

Cancer BACUP: Europe's leading cancer information service, with over 4,500 pages of up-to-date cancer information, practical advice and support for cancer patients, their families and caregivers. Search the site for the term Lymphedema and Manual Lymph Drainage.

<http://www.cancerbacup.org.uk>

## b. Books

Coping With Lymphedema

by Joan Swirsky, Diane Sackett Nannery

The original book about lymphedema prevention and maintenance with great relevance for the breast cancer patient. A great addition to your health library.

Lymphedema - A Breast Cancer Patient's Guide

by Jeannie Burt, Gwen White

An easy-to-read guide for the breast cancer patient about prevention and help with lymphedema. Helpful hints and good strategies for dealing with the potential complications. Has Illustrated self-massage instructions on pages 55-62.

Lymphedema Handbook: Prevention and Management Strategies for People With Cancer

by Ellen Carr, Linda T. Miller, Ruth, Ph.D. McCorkle

This handbook provides a practical overview for the prevention as well as management of lymphedema, a complication that sometimes occurs after breast cancer treatments.

(Alameda, CA, Hunter House Inc. 1999).

Lymphedema An Information Book for Patients, Their Medical Practitioners and Health Care Workers  
By Judith R. Casely-Smith and J.R. Casley-Smith. Tenth edition, January 2003.



Lymphedema A Breast Cancer Legacy  
Breast Cancer Action Ottawa  
Order by writing Breast Cancer Action at Billings Bridge Plaza, PO Box 39041, Ottawa, ON K1H 1A1 (613) 736-5921



### c. Glossary of lymphedema related words

Axillary Node Dissection: Lymph nodes under the arm are removed during surgery.

Compression Garments/Sleeve: Two-way stretch garments that aid in controlling swelling

Combined Decongestive Therapy (CDT): The most effective treatment for lymphedema. CDT includes: Manual Lymph Drainage (MLD), Compression Therapy, Decongestive Exercises, Skin Care and teaching patients how to take care of themselves in a new way.

Decongestive Exercises: Exercises to help lymph flow and over time, decrease swelling

Fibrosis: Hardening of body tissues

Lymph Nodes: Small, bean-shaped organs with special cells that can trap cancer cells or bacteria that are traveling through the body in lymph. Also called lymph glands.

Lymphatic System: The tissues and organs, including the bone marrow, spleen, thymus, and lymph nodes, that produce and store cells that fight infection and disease. The channels that carry lymph are also part of this system.



Lymph Fluid: A clear watery fluid that travels through the lymphatic system and carries cells that help fight infection and disease.

Manual Lymph Drainage: A gentle manual treatment that helps lymph fluid find new ways to flow around blocked areas into healthier lymph vessels. This special type of massage uses light strokes that are done in a certain pattern along the lymphatic vessels and tissues around them.

Self-massage: A massage that you do yourself between lymphedema treatments. It is a form of Manual Lymph Drainage (MLD). Your therapist will teach you the movements that will work best for your treatment.

### 13. My Health Care Providers

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_







## Insert

- Treatment
- Where To Get Help

Use this pocket to keep brochures and other information you gather during appointments with your health care providers.



This booklet is a project of:  
Thunder Bay Regional Health Sciences Centre,  
Regional Cancer Care.



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