

# *Guide to Lymphedema*

The M. Lau Breast Centre



Princess Margaret Hospital  
University Health Network

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## Message from Director

Medical advances in early diagnosis and treatment of patients with breast cancer have had a huge impact on the chances for long term survival, and more than two thirds of patients can now expect to live over twenty years. These treatment successes have come at a cost however, and many breast cancer survivors are now living with the long term consequences of these medical therapies.

Upper limb lymphedema is a common and distressing complication of breast cancer surgery. The reported incidence after surgery is 10%, and the risk increases substantially following the administration of postoperative radiation therapy. It is a chronic and progressive condition, and patients can suffer a variety of physical, emotional and psychological symptoms. There are a number of treatment approaches including compression bandaging and manual lymphatic drainage that survivors and or their family members can be taught how to apply.

The Princess Margaret Hospital Breast Cancer Survivorship Program introduced an upper limb lymphedema clinic in April, 2005, to address the needs of survivors who were concerned about developing lymphedema or who were suffering from it. Survivors indicated they wanted programming that would provide education, support, clinical care and research, and we are attempting to answer these requests within our comprehensive Survivorship Program.

This education booklet has been developed by breast cancer survivors and a large team of health professionals working in the Breast Cancer Site Group and the Survivorship Program. This booklet has been adapted from the education sessions conducted in the Lymphedema Clinic, and addresses two important questions:

1. What can I do reduce the risk of developing lymphedema?
2. What can I do to manage lymphedema if it occurs?

We hope you find the information informative and helpful in adopting healthy behaviors and useful strategies that can reduce the risk and help manage lymphedema.

Pamela Catton MD MHPE FRCPC  
Medical Director  
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## Introduction


This booklet is intended as an educational guide for persons at risk of developing lymphedema after breast cancer treatment. It is not intended to replace medical treatment or advice from a qualified health care practitioner.

This booklet contains basic information, to help you learn about lymphedema to improve your own sense of well being. As much as possible, the information has been gathered from research.

Lymphedema is a health condition that requires attention. It is not life threatening, but living with it may make you feel uncomfortable. It can affect your self-image, the clothes you wear and interfere with your regular activities. It can also be an emotionally painful reminder of your breast cancer experience.

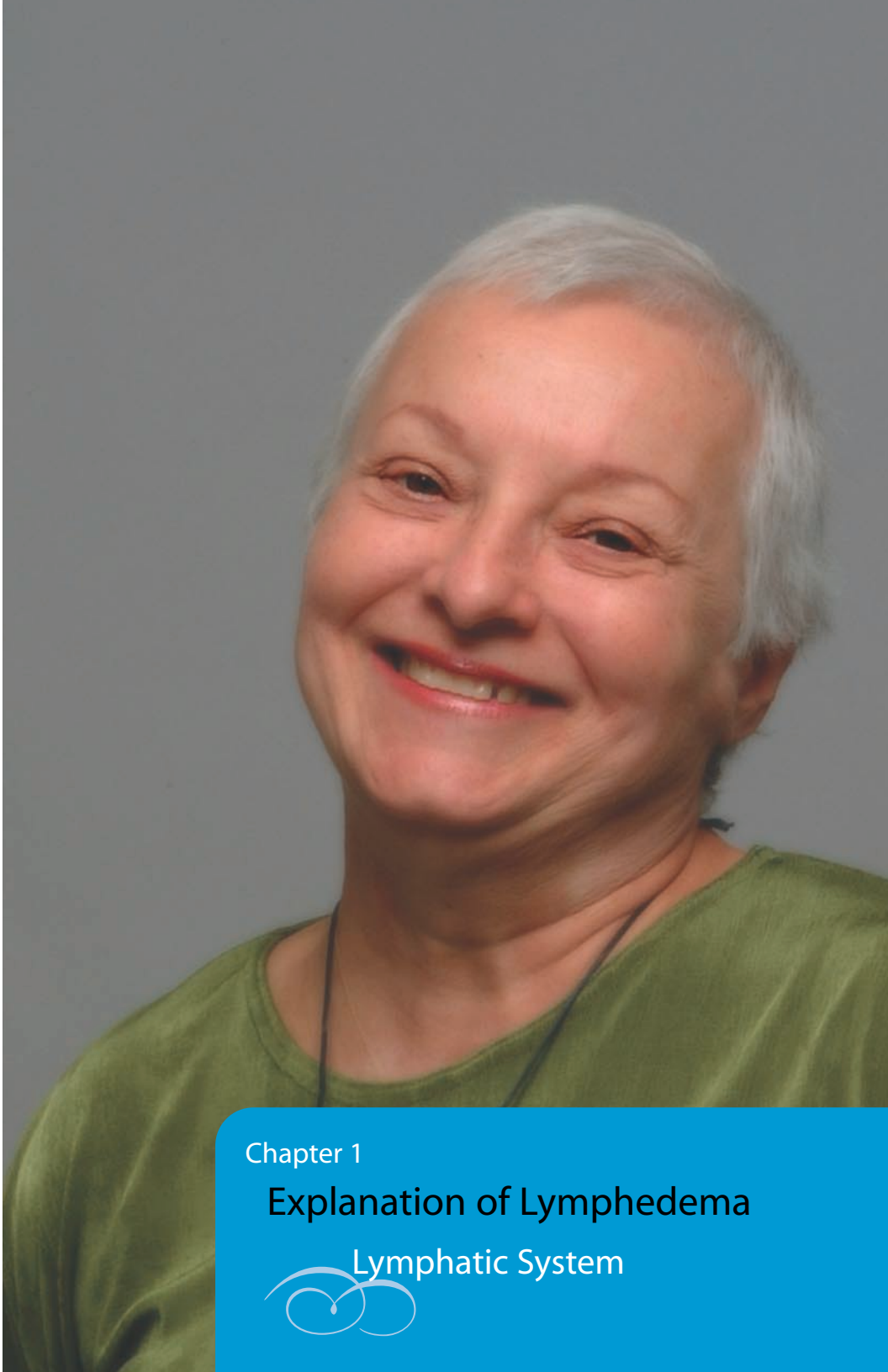
Lymphedema can effect your emotions as well as your body. It might remind you of the cancer that was treated. It is normal to have many different feelings. You may feel angry that your life has been disrupted again or that not enough was said to warn you about this condition. You may feel “validated” that you have a real condition that is a result of your treatment and can be managed. You may feel frustrated that management of the swelling and pain takes up so much of your time and money. Your mood might lighten as you realize that it is not your cancer coming back. Whatever your feelings, it is important you have someone to talk to. Family, friends, health professionals and survivors with the same condition can help.





*“The only feelings that do not heal  
are the ones you hide.”*

*– Henri Nouwen*



Chapter 1

## Explanation of Lymphedema

Lymphatic System





# What is LYMPHEDEMA?

(Sounds like = lim-fe-DEE-ma)

**Lymphedema** is a condition that occurs when lymph fluid cannot drain waste away properly. Everyone has a colourless fluid, called 'lymph' fluid, moving through a system of vessels called **lymphatics** (Figure 1). The extra fluid builds up in between the cells of the soft tissues. The build up of protein rich lymph fluid can cause swelling in your arm, hand, chest, breast or back.

Chances of getting lymphedema in breast cancer patients are 10% from surgery alone, increasing to 20-30% when treatment includes radiation therapy.

This means that as a survivor, if you had surgery and radiation treatment for breast cancer, you are at risk for developing lymphedema.

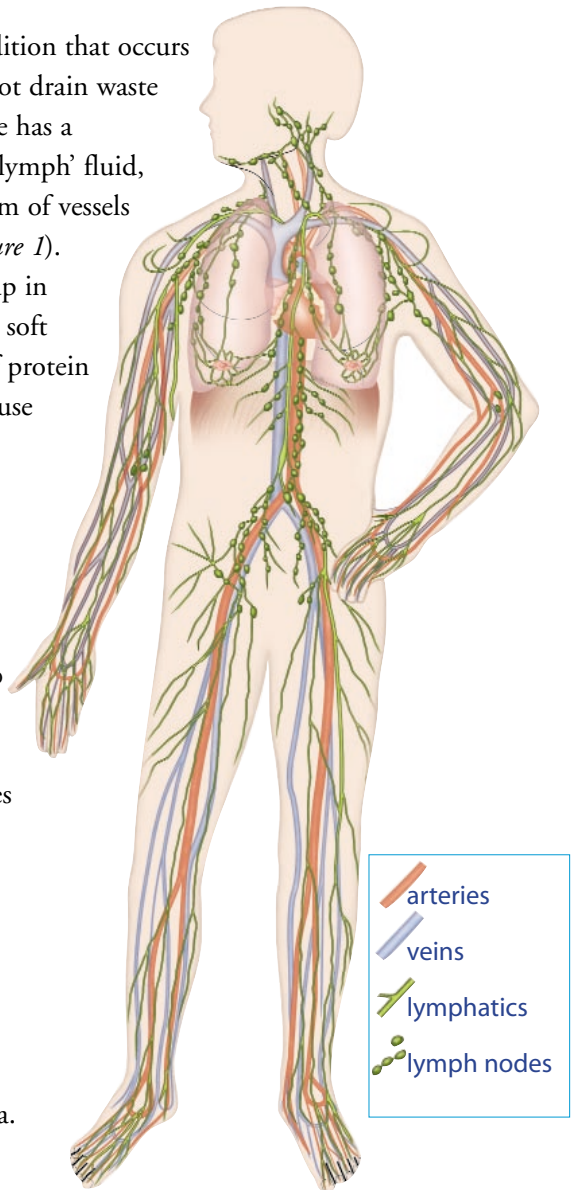


Figure 1. Lymphatic System in relationship to circulatory system

# The Lymphatic System

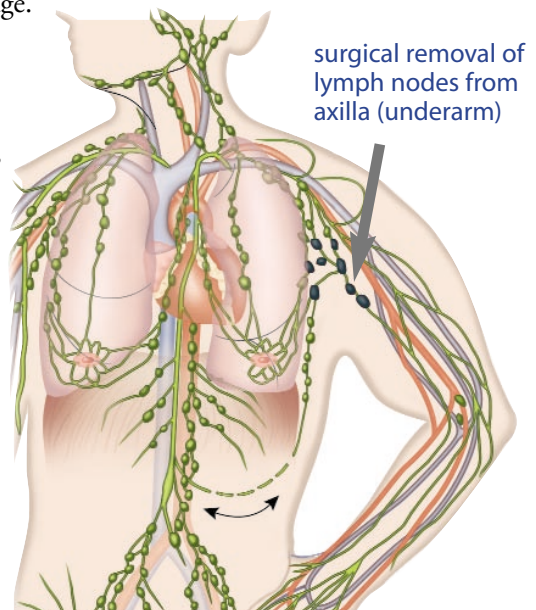
Surgery, radiation treatment, chemotherapy, infection and/or injury can change the normal flow of lymph fluid throughout the lymphatic system. These changes can put strain on the upper body.

Your body can develop new pathways for the lymphatics to drain the lymph fluid away. But sometimes the new pathways do not drain all of the fluid. This build up of waste in the lymph fluid can result in lymphedema.

Your risk for lymphedema depends on how well your body can adjust to any of these changes.

When your body reaches a point where the extra fluid can be seen and measured, health professionals call it **Secondary Lymphedema**, which is a fluid build-up as a result of the treatment (*Figure 2*). This extra fluid means the workload in your arm or chest is more than your lymph system can manage.

Each person is different. Lymphedema can appear right after treatment (surgery, chemotherapy, radiation) or much later, maybe even decades later. Getting to know the changes in your body after treatment will help you notice the signs that you may be developing lymphedema. These changes will let you know to take action to bring your body back into balance.



**Figure 2.** Lymphatic Pathway of arm is blocked at underarm where lymph nodes were removed



*“Yesterday is gone.  
Tomorrow has not yet come.  
We have only today. Let us begin.”*

*– Mother Teresa*



## Chapter 2

# Reducing Risk of Developing Lymphedema





# Reducing Risk of Developing Lymphedema

## Knowing Your Risk

Anyone who has had his or her lymph nodes removed is at risk for lymphedema. They are removed to find out the best treatment approach after surgery.

The chance of developing lymphedema increases when you receive radiation treatment to your underarm. Radiation is used as a treatment for your cancer. It causes a change in the tissues. Overall, the benefits of radiation outweigh the risks.

There are other risk factors that may increase your chance of swelling:

- Obesity
- Smoking
- High blood pressure
- Diabetes
- Infection in the affected side
- Injury to the affected side

Think about how you can make changes in your lifestyle to lessen the workload of your body, and by doing so you can lessen your risk.

## What May Trigger Lymphedema

**Trauma to Arm:** Any injury increases fluid in the arm from the healing response. It may also lead to infection if the skin is broken. This can include bug bites, scratches, a sunburn, kitchen burns, plant rashes, garden cuts, cracked skin from dryness or skin tears from picking habits.

**Gaining Weight After Treatment:** Extra weight can increase your risk for arm swelling.

**Heat:** Heat allows more fluid into an area since it widens the blood

vessels. Very hot weather or sitting in a hot tub can bring on lymphedema.

**Blood Clots:** Occasionally, a blood clot in the underarm will back up fluid in the arm.

**Extensive Breast Cancer in the Lymph Nodes:** This uncommon cause of lymphedema can happen if the cancer is blocking the flow of lymph fluid that should be draining through the nodes.

## What You Can Do for Yourself

Following common sense lifestyle changes is your best way of helping your body to cope with, through and beyond your cancer experience. These suggestions, although not based on research, are meant as a guideline for reducing risk. Even if you follow them, you may still develop lymphedema.

Skin care, healthy body weight and circulation are areas that you can have control over and may reduce the impact of lymphedema on your life.

### 1. Look after your skin

Healthy skin is your body's best defense against infection. Since an infection in your affected arm may make it swell, try to avoid any injury to your skin. The Look Good Feel Better program is a good way to get tips about skin care, as well as other appearance related issues throughout your experience. Ask for the Look Good Feel Better brochure and magazine in the Patient & Family Library at Princess Margaret Hospital.

Here are tips on how to best look after your skin:

- Keep your skin clean using mild soaps and pat dry.
- Moisturize often with a deep penetrating cream.
- Apply the cream while skin is still moist so it absorbs into the skin deeply.

- Use caution when shaving your underarm. During surgery, nerves may be damaged resulting in less sensation to the area. You are more vulnerable to nicks and cuts even with an electric razor.
- Wear insect repellent to avoid bug bites. Any ‘bite’ can trigger the healing response, making your body work extra hard.
- Clean any breaks in your skin with soap and water, apply an antibiotic ointment to the cut (e.g. Polysporin or Ozonol), and cover with a bandage. As an alternative you could use ‘liquid bandage’ to cover the wound.

As much as possible **avoid:**

- Extreme heat especially when bathing, including hot tubs and saunas. Your blood vessels will dilate and fluid will build up. Alcohol and caffeine also dilate blood vessels.
- Chemical hair removers under the arm. They may irritate and leave the skin raw.
- Injury to your skin that could lead to infection, such as pinpricks, pet scratches, rose thorns, burns or acupuncture.
- Extreme temperature changes when washing the dishes.
- Harsh soaps or detergents that may irritate your skin, causing raw areas where bacteria can enter.

**Nail Care:**

- Keep your fingernails short.
- Soak your nails in slightly warmed olive oil (10 seconds in the microwave). This nourishes brittle nails and can prevent breaking.
- Soften cuticles with cream or oil to help prevent hangnails, splitting and dryness. Try pushing back with a washcloth after soaking in warmed olive oil.

*“I made a commitment to live when I put on nail polish... I thought, ‘It looks nice’. I started to like myself again. I started to like that part of my body.”*

*– PMH Survivor*

- When manicuring your nails use a soft sided emery board.
- Use an acetone free nail polish remover.
- Treat yourself to a manicure. Manicurists who use disposable equipment are best.
- Avoid nail scissors or clippers.
- Don't cut your cuticles.
- Don't bite your nails.
- Don't pick at the skin around your nails.
- Avoid artificial nails. The acrylic used can increase the risk of fungal infection.

Remember to **protect your hands and arms** when:

- Cleaning
- Gardening (*Figure 3*)
- Riding (horses, bicycles)
- Cooking, (use **long** oven mitts)
- Sewing (use a thimble)

### **When in a Hospital, Clinic or Lab:**

Even though there is no research evidence that suggests blood collection techniques can bring on lymphedema:

- When possible avoid needles in your affected arm, such as injections or having blood taken.
- Discuss with your health care team the use of your treated side for blood collection and chemotherapy. It might have to be used for you to have effective cancer treatment.
- It is sometimes necessary to use the affected arm for drawing bloodwork or for intravenous therapy.
- Remind the staff in the Blood Lab and Imaging department that you have had surgery in your underarm.
- Have your blood pressure taken on the opposite side.



Figure 3



**Protecting Your Skin In the Sun: a message from our Pharmacist**

A sunburn to your arm causes fluid to be sent to that area in order to repair the sun damage. In some people, this may be enough to start a swelling of the arm. Any hypoallergenic sunblock with an SPF of 30 or greater is recommended. This degree of sunblock chemically protects against both UV-A and UV-B. Also a sunblock with titanium dioxide that acts a physical shield is highly recommended. One recommended product available at the most pharmacies is *Ombrelle SPF45 with titanium dioxide*.

Apply sunblock liberally and evenly to all exposed areas of the skin 15 to 30 minutes before sun exposure and reapply every two hours especially after swimming or heavy perspiration. In this way, you can reduce your risk of triggering lymphedema.

**2. Maintain a healthy body weight**

Obesity is a risk factor for lymphedema. It is defined as having a body mass index (BMI) of 30 or higher. You can check your BMI range by finding your height on the charts below. (*Table 1 and 2*)

**Table 1: Body Mass Index in Pounds**

Height	Weight Ranges		
	Desirable	Overweight	Obese
5' 0"	95-126 lb.	127-151 lb.	152 lb. or more
5' 1"	97-130 lb.	131-157 lb.	158 lb. or more
5' 2"	101-137 lb.	138-164 lb.	165 lb. or more
5' 3"	105-141 lb.	142-168 lb.	169 lb. or more
5' 4"	108-145 lb.	146-175 lb.	176 lb. or more
5' 5"	112-150 lb.	151-180 lb.	181 lb. or more
5' 6"	114-154 lb.	155-185 lb.	186 lb. or more
5' 7"	119-159 lb.	160-190 lb.	191 lb. or more
5' 8"	121-163 lb.	164-197 lb.	198 lb. or more
5' 9"	125-167 lb.	168-201 lb.	202 lb. or more
5' 10"	130-171 lb.	172-209 lb.	210 lb. or more
5' 11"	132-178 lb.	179-213 lb.	214 lb. or more

Table 2: Body Mass Index in Kilograms

Height	Weight Ranges		
	Desirable	Overweight	Obese
152 cm	43-57 kg.	58-68 kg.	69 kg. or more
155 cm	44-59 kg.	60-71 kg.	72 kg. or more
158 cm	46-62 kg.	63-74 kg.	75 kg. or more
160 cm	48-64 kg.	65-76 kg.	77 kg. or more
163 cm	49-66 kg.	67-79 kg.	80 kg. or more
165 cm	51-68 kg.	69-81 kg.	82 kg. or more
168 cm	52-70 kg.	71-84 kg.	85 kg. or more
170 cm	54-72 kg.	73-86 kg.	87 kg. or more
173 cm	55-74 kg.	75-89 kg.	90 kg. or more
175 cm	57-76 kg.	77-91 kg.	92 kg. or more
178 cm	59-78 kg.	79-95 kg.	96 kg. or more
180 cm	60-81 kg.	82-97 kg.	98 kg. or more

Weight loss may reduce your risk of developing lymphedema if you are obese. Consult your general practitioner for a referral to a registered dietitian or look on the Dietitians of Canada website, [www.dietitians.ca](http://www.dietitians.ca), to find a consulting dietitian in your area. This website also has information on portion control, overcoming obstacles to healthy eating and adding physical activity to your day.

Any weight loss effort should include physical activity. Make sure that the exercise you start is safe for your condition

*“Obesity is a risk factor for lymphedema,  
as well as being a risk factor for recurrence.”*

*– March 2006  
PMH Lymphedema Workshop*

### 3. Improve the circulation in your arm

It is important to move your arm daily through a full range of motion to maintain flexibility and regain or maintain your strength. Moving your arm and contracting the muscles as you do exercise will help move fluid through your arm. Be sure to follow a daily activity program, starting with walking, so you can participate in your favourite activities.

Check with your doctor before beginning a new activity or sport. Follow the advice of your physiotherapist on how to improve your activity level.

You may do some form of light aerobic activity (swimming, walking, biking, dancing, light aerobics). Aerobic activity has many different health benefits, including improving lymphatic flow.

Increase your exercise slowly and be aware of how your body responds. If your arm aches afterward, you may have overdone it. If so, lie down, rest and elevate your arm.

- Elevate your arm above the level of your heart, when sitting or lying down. Do this several times a day if you find it helpful.
- Support your arm on several pillows when sleeping or travelling.
- Open and close your fist several times throughout the day

Exercise has many benefits for your arm and for your whole body. It can make muscle tone better, help the mobility of the joints, and improve the lymphatic and blood flow, making it easier to cope with any increased weight of the arm.

*“Be active, but be cautious.”*

*– March 2006*

*PMH Lymphedema Workshop*

For more tips and general information about activities such as walking, gardening, golf or computer station set-up (ergonomics), please visit the Canadian Physiotherapy Association website at [www.physiotherapy.ca](http://www.physiotherapy.ca).

### Exercise Tips:

- Follow a regular program of safe, gentle stretches and exercises (*Figure 4*).
- Begin your activity slowly.
- Gradually increase the length of time you exercise.
- Avoid sharp, jerking movements that may strain your joints or injure your muscles before they are strong enough to cope.
- Avoid leaning your body weight onto your arms, especially if you are on a bicycle with dropped handlebars.
- Use weights in a gradual manner.



**Figure 4.** Exercising at work

By keeping the circulation flowing in your arm, you may avoid a backup of fluid that can overload your lymphatic system.

### Use of light weight compression garments:

It would be beneficial to support the skin and tissues of the arm during activities that put extra stress on the upper body.

- If your goal is to eventually try a more vigorous sport such as golf, tennis, skiing, or rowing, work your way up to it carefully, while wearing a light compression sleeve.
- Also while gardening, swimming and other hobbies (*Figure 5*).

### Strain prevention and reduction tips:

- Carry your bag over the non-affected shoulder.
- Wear a bra with wide straps that fits well.
- Use wide straps on handbags and backpacks.
- Avoid tight clothes.
- Avoid tight fitting jewellery. Bracelets and watches can be fitted with links that will make them loose.

Certain activities may slow down the lymph flow from your arm to the body, particularly repetitive motions or carrying heavy items. Please avoid the following:

- Carrying heavy grocery bags.
- Carrying, pushing or pulling suitcases, briefcases or laptops.
- Vacuuming.
- Lifting heavy boxes.
- Rolling paint on a wall.
- Using a computer for more than one hour.
- When travelling by airplane, be sure to walk down the aisle and stretch your arms and legs as often as you can.
- Remember your moisturizer, antibiotic cream and bandages on the plane. Keep your arm elevated as much as possible throughout the flight.
- Recent studies do not agree that wearing a sleeve while traveling by airplane reduces your risk of triggering lymphedema. More research needs to be done in this area.



Figure 5. Light compression garment worn

*“I’ve had lymphedema for so long that I know when I use the computer, it’s going to hurt. It is better with rest ...definitely triggered by gardening ...everyone needs to learn what the unique triggers are for them.”*

*– PMH Survivor*



*“If you have knowledge,  
let others light their candle in it.”*

*– Margaret Fuller*



## Chapter 3

# Warning Signs of Lymphedema





## Warning Signs of Lymphedema

There is no way to predict if you will develop lymphedema, but enough people have described their experience that we feel confident in giving you these guidelines.

Some people say they:

- Feel heaviness in the arm.
- See swelling of the fingers, hand or anywhere along the arm (*Figure 6*).
- Feel a sensation as though there was an egg or golf ball in their underarm.

Remember: some swelling after surgery, called **post surgical edema**, is due to your body's natural healing process. This is normal and may not mean you have lymphedema. The post surgical edema is expected to clear up when the area heals.

Your best defence against lymphedema is to **detect it early**. As part of your daily activities, take a few minutes to check for changes in your body on the side of your surgery. Lymphedema can also affect your chest, breast, trunk, shoulder and the area behind your shoulder.

### Monitor for Lymphedema



**Figure 6.** Bend your arms up and look at the elbow area in the mirror

### *Stemmer sign test*

Pinch the skin on your arm or hand on the affected side and then compare it to your other arm (*Figure 7 and 8*). When swelling accumulates, your skin may seem thicker and it will be more difficult to pinch.



Figure 7. Negative



Figure 8. Positive

### Measure for Lymphedema

- Changes in size between arms greater than 2.5cm measured at the same area as your other arm. Your 'dominant' arm or the one you use most is usually slightly larger.

## Infection

Infection is a common concern for survivors of breast cancer. Lymph nodes are a part of the immune system. They filter and destroy bacteria and viruses. So when the lymph nodes are removed from the underarm, it makes a person more vulnerable for infections in that side of the upper body.

Local infections can lead to the more serious kind called cellulitis. (Figure 9) This type of infection can spread quickly along the lymphatics, drawing a lot of fluid to the area. It is known to trigger lymphedema or make the condition of lymphedema worse. If cellulitis is left untreated, the infection can travel through the blood stream to become septicemia, a very serious infection that affects the whole body.

It is important to try to prevent the local infections by looking after the skin (page 19), and also by recognizing signs and symptoms of cellulitis and septicemia (Table 3).

If you have been diagnosed as having the condition of lymphedema, you are at a higher risk for developing cellulitis, since the sluggish lymph fluid in the tissues is a perfect place for bacteria and viruses to colonize.

Table 3 summarizes how to recognize and manage infections in the upper body on the side where the lymph nodes have been taken out.



Figure 9. Sign of cellulitis

**Table 3: Take action when you notice these important warning signs of infection**

LOCAL INFECTION	SERIOUS INFECTION
<p>What does it look like:</p> <ul style="list-style-type: none"> <li>• reddened area found at break in skin, common around nail beds</li> <li>• mild swelling where there is redness</li> <li>• may be from cut, scratch, scrape, prick, insect bite, burn</li> <li>• there may be a discharge from the open area, may be greenish tinged</li> <li>• tender to touch</li> <li>• no fever = oral temperature lower than 38C (100.5F)</li> <li>• redness may slowly spread around the area of the break in skin and edges become thick and raised</li> </ul>	<p>What does it look like:</p> <ul style="list-style-type: none"> <li>• starts as a bright red patch on arm, breast or trunk</li> <li>• quickly begins to spread and may streak upwards</li> <li>• may look like a mild sunburn</li> <li>• skin is pinky-red, slightly raised and may look like the skin of an orange</li> <li>• swelling where there is redness</li> <li>• tender to touch</li> <li>• the area may feel warmer than the other side</li> <li>• oral temperature of 38C (100.5F) or higher with no cold or flu symptoms</li> </ul>
<p><b>WHAT TO DO</b></p> <p>Look after it yourself:</p>	<p><b>** IMMEDIATELY seek help **</b></p>
<ul style="list-style-type: none"> <li>• wash immediately with mild soap and water or saline solution (page 26 in Getting Back on Track booklet)</li> <li>• rinse gently under running tap water or pat carefully moving gauze from break in skin away from it as you pat dry</li> <li>• Use an antibiotic ointment and cover (or use liquid bandaid)</li> <li>• Change the cover and reapply the ointment daily until healed</li> </ul>	<ul style="list-style-type: none"> <li>• try your family doctor first</li> <li>• try your oncologist next</li> <li>• if they are not available DO NOT WAIT for your next appointment!!</li> <li>• try a walk in clinic</li> </ul> <p>If all the other options are not available:</p> <ul style="list-style-type: none"> <li>• go to the EMERGENCY Department of your local hospital. Tell whoever sees you that you have had lymph nodes removed and need to have antibiotics if there is cellulitis present</li> <li>• the doctor will be able to check if it is or is not an infection</li> <li>• may check if it is a blood clot in the arm (similar symptoms of swelling, redness, tenderness and warmth)</li> </ul>

## Diagnosis of Lymphedema

A physician can help figure out if you have lymphedema, an infection, a blood clot blocking a vein (deep-vein thrombosis), or a return of your cancer in the underarm or chest wall.

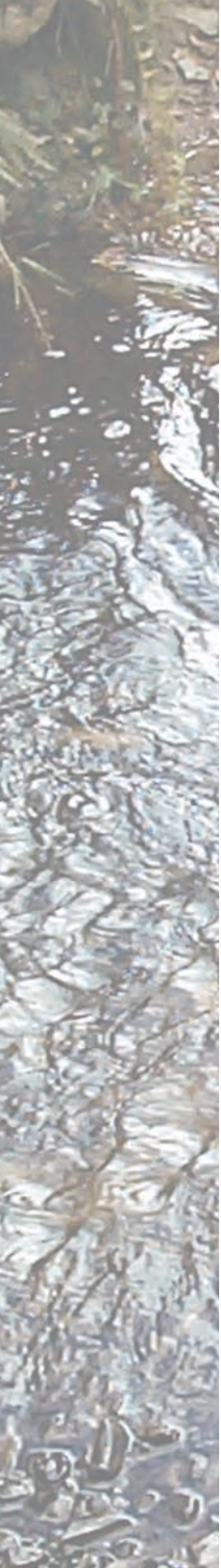
There are tests that can be done to check for other causes of the swelling. The doppler ultrasound, C.T. scan and M.R.I. are some of the more common tests used.

Medication can be given to treat infections and clots and the swelling should go away. If the cancer returns, your doctor will talk about treatment options. If your doctor believes you have lymphedema, a referral to the Lymphedema Clinic at Princess Margaret Hospital can be made.

*“Once you become aware, you can never become unaware. Once you have been through this, it just changes everything so that your relationships, your spirituality, everything you look at is different. But it is the same among survivors.”*

*– PMH Survivor*





*“I enjoyed being in the company  
of other lymphedema patients,  
I feel less alone about my lymphedema.”*

*– PMH Survivor*



Chapter 4

If Lymphedema Happens to You

Living with Lymphedema





## Living With Lymphedema

### Lymphedema is not your fault!

Your body is just unable to manage the workload in your upper body. With your help a plan of care, that is a combination of things that you can do for yourself and what experts can do for you, can be developed. Once the diagnosis of lymphedema is made, the health care professionals involved in your care may include a doctor, nurse, physiotherapist, registered garment fitter, registered massage therapist, occupational therapist, dietitian and social worker (*Figure 10*). The goal is to give you the knowledge, skills, and support to live your life to the fullest.

Like most chronic conditions, there is no one answer that can clearly resolve your physical and emotional issues. Each person has different needs.



**Figure 10.** Multidisciplinary Team at the March 2006 PMH Lymphedema Workshop

### Managing your Lymphedema

The swelling caused by lymphedema can be controlled and may even go away, but the changes that brought on the swelling may not be reversible. You will always be at risk for infection and there is a chance the swelling may return. Since lymphedema is a progressive condition,

one goal is to move fluid out of the tissues to reduce the symptoms you feel. Other goals may be to support the skin and tissues of your arm, and to prevent the complications of infection, fibrosis (thick, tough skin and tissue) and immobility. Your **health care team** at Princess Margaret Hospital **provides support and will help you identify choices** as to how you would like to manage your care.

Now that you have been diagnosed with lymphedema these are some of the things you may consider:

### Become well informed!

- **Attend** an information session about lymphedema; a schedule can be found on the Breast Cancer Survivorship calendar [www.survivorship.ca](http://www.survivorship.ca)
- **Be** even more **aware** of signs of infection!
- **Review** risks (*page 8*).
- **Enroll** in the Breast Cancer Survivorship Program for ongoing support.
- **Visit** the PMH Patient & Family Library on the Main floor. The staff will help you find the information you need.

### Manage the physical symptoms of your Lymphedema

The four cornerstones of physical management are skin care, lymphatic massage, compression, and exercise:

#### *Skin Care: (page 9)*

- Inspect your skin daily especially around the nails and folds in your skin. Soften the cuticles and push back gently. Never use an instrument that can break the skin.
- Work with your health care team to monitor your symptoms.
- Recognize and manage changes in your skin and tissue:
  - An area of your body with lymphedema will have a harder time fighting infection (*page 22*). This infection can travel

through the skin of your arm (cellulitis) and if not treated, enter your blood stream (septicemia). Both are very serious and need attention from a doctor (*page 23*).

- Participate in a Look Good Feel Better workshop.

### *Lymphatic Massage*

Learn self-massage. The purpose is to make spaces for the lymph fluid to drain into.

- The massage for helping lymph flow is different than a deep muscle massage and should be done gently, starting at an area the furthest away from the swelling. The pressure by the pads of your fingers is very light. It has been described as “stroking a bird or kitten” or “as gentle as a butterfly kiss”. This creates a space for the fluid to go into. You can then move to the next area. Do not ‘squeeze the muscle’ in the affected limb, as it will increase the circulation to the area (more fluid) and may cause damage to the lymphatics or tissue.
- A member of your support team could also learn and do this type of massage for you.
- We offer you education about lymphatic self massage through four sessions in the clinic with a registered manual lymph drainage specialist.

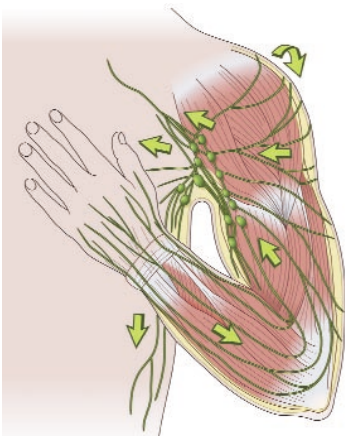


Figure 11. Movement pumps lymph fluid towards the lymph nodes

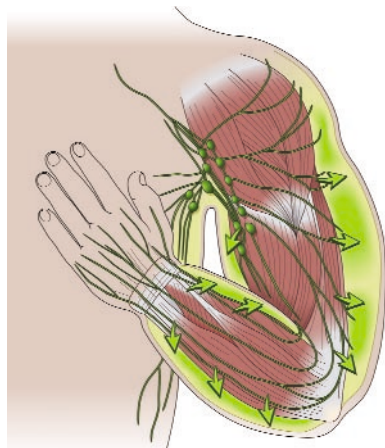


Figure 12. Blocked lymphatic pathway causes lymph fluid to pool in tissues

- Instructions for this kind of massage will be discussed in the clinic or can be obtained from the library.

You could go for Manual Lymph Drainage with a specially trained 'lymphedema' therapist. This is highly recommended for moving the fluid out of your limb and making new passages for the lymph fluid to travel back into your circulation. The therapist is able to reach areas difficult for you to do yourself, such as across the back. Although it is not covered under the government plan, you may be covered under your insurance policy. Each session is usually less than \$100. A list of Registered Therapists can be provided to you or found on the Internet. See [www.vodder.school.com](http://www.vodder.school.com) under Find a Therapist.

### *Compression:*

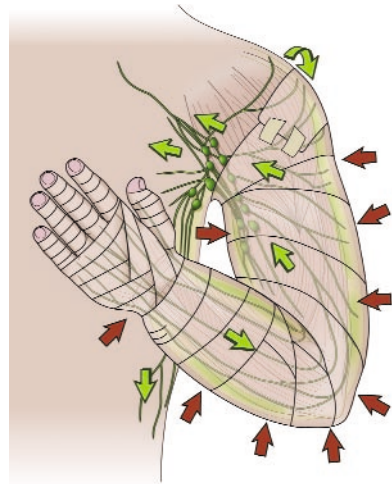
Choose compression that suits your lifestyle. Your healthcare team can explain and show examples of the different types of compression available. These can be used in combination depending on your unique situation. New swelling is often controlled with bandages, before a decision is made about which garment would be best.

Another method of moving fluid is to use a compression pump.

Compression by bandages or garment helps your own body move the lymph fluid to the heart by supporting your skin and tissues (*Figure 11, 12 and 13*). It also protects your skin and helps keep it from stretching out of shape.

**Bandaging** is recommended whenever the swelling is still changing.

- Use short-stretch bandages (e.g. Comprilan). You and your caregivers will be taught how to wrap your arm. Written instructions will be given as well.



**Figure 13.** Supporting the skin helps prevent over stretching and moves fluid past the obstruction

- If you are unable to do the bandaging yourself, there may be nurses in your community who could help you through CCAC.
- Continue to do your daily activities. The bandages work best when they help support the action of your arm muscle pumping on the lymph vessels.
- The cost of the bandages is usually under \$100. Sometimes this may be more than you can afford, but this should not prevent you from having this treatment. Let us know right away if this is a problem and we can help.

**Compression Garment** of a sleeve, glove, vest and/or bra is recommended when the swelling stays the same for a period of time.

- You will be sent to a registered fitter. They are specially trained to measure you for best fit of your garment.
- It is recommended you have two sets so that you can still wear one while the other is gently washed and air-dried.

- Wearing a rubber glove on the non-affected arm will help get the garment on. Sometimes tiny amounts of a special gel can help the sleeve on more easily. This can be purchased where you get your garment.



Figure 14. Learning to bandage

- You could start by wearing the sleeve for a few hours to get used to it.
- It can be worn all day and taken off at night or when resting.
- Wear your compression garment **regularly**.
- You should wear it when you are doing any strenuous activity.
- The garment is replaced when the elastic wears out.

This depends on how long you wear it and how active you are. Usually a new set is bought every 4-6 months.

*“Research shows that the long-term, daily use of compression garments for lymphedema will result in an improvement.”*

*– March 2006*

*PMH Lymphedema Workshop*

- If you do not have Insurance, then papers for government assistance can be filled out for you in the clinic. You would then take the Assistive Devices Program (ADP) form to your registered fitter. This Government program supports 75% of cost. These garments cost between \$300.00-\$400.00 per set.

**Intermittent Pneumatic Compression Pump** works by putting pressure on the tissues on your arm. Fluid is pushed back into the blood stream. You would put a pump therapy sleeve on. The pump would push air into the chambers of the sleeve, one at a time, until it is fully inflated. If used alone the pump therapy may lessen the fluid in your arm at first, but studies have shown the fluid comes back. Research studies report that they are not any more effective than the compression garment when used alone. We recommend wearing bandages or a garment as soon as you take the pump therapy sleeve off.

- It is advisable to be fitted for a garment as soon as the pump has helped bring the size as small as it can be. The garment would then help to prevent the fluid coming back.
- Your insurance policy may cover the cost.
- Compression pumps are available for rent (\$250.00 / mo.)

*If you choose to wear a sleeve, glove or bandages, it would be best to put them on after the massage and before exercising.*

*Exercise: (page 14-15)*

- Muscle action helps move the lymph fluid out of your limb and improves your circulation.
- A physiotherapist will give you special exercises if you have any difficulty with movement (*Figure 15*).



**Figure 15.** Physiotherapist teaching lymphatic exercises

- An occupational therapist will give you help if you have trouble with your activity.
- Physiotherapists and occupational therapists can provide valuable advice to help you resume your day-to-day activities related to family life, leisure or work.
- Exercise regularly.

*Monitor and report discomfort*

Tell us what kind of discomfort you feel. You may want to keep a diary to describe how you feel and how often. Scoring each type of discomfort on a scale of 0-10 daily in your diary would help you report changes.

## The Lymphedema Clinic provides:

- **Education**

The clinic gives information in a variety of ways to help you understand what the condition of Lymphedema is and what can be done about it (*Figure 16*). The team can tell you about current research studies and those you could participate in.

- **Assessment**

- The team will measure your limb to determine how much extra fluid you have.
- Skin, tissue density, function, range of motion, pain and fatigue are also checked.
- Your social, emotional concerns can be discussed.

- **Management**

- You will create a Care Plan suited to your lifestyle (with the help of your team) to manage the symptoms of Lymphedema and reduce the risk of complications.



**Figure 16.** The clinic gives information in a variety of ways



- There will be referral to experts in fitting for garments, Lymphatic Drainage and community services.
- The team will recommend types of compression that are best suited for your type of swelling.
- The team will suggest ways to help reduce the discomfort.
- A sequential pump treatment experience can be provided in the clinic.
- You will be assisted to connect with other health care professionals and community supports, such as the Lymphovenous Society.
- Together we can discuss the less common ways of looking after the Lymphedema found in the community:
  - Kinesio Taping
  - Alternate types of sleeves
  - Selenium
  - Hyperbaric Oxygen
  - Laser
  - Microvascular Surgery
  - Explanation is given as to why medications like diuretics (short term effect not sustainable) or Coumarin (a study showed a few patients developed liver damage) are not used
  - Being registered in the clinic database helps us keep you updated as new programs develop

• **Surveillance**

The clinic will provide support and be a resource for choices as to how you would like your follow-up of the lymphedema. We are meant to be a stepping stone for you to be able to live the best way you can in your own community.

## Think about your feelings.

Tell us if living with lymphedema is keeping you from doing the things you would like to.

- Many people like talking to others with the same problem. You could come to the Breast Survivorship “Talking Sticks” Program to meet some of these people and exchange ideas and feelings (see Calendar of Events).
- Let us know right away if you feel you are not coping or your emotions are overwhelming you.



Figure 17

*“The nurse pointed out where I was effective and where I wasn’t effective in terms of my lymphedema self-management. I learned that I didn’t use bandages as much as I should. I realized I needed to exercise more.”*

*– PMH Survivor*



*“I’m just thrilled that these are professional people. They know what they are talking about. I can ask all kinds of questions. The information was very good.”*

*– PMH Survivor*



## Chapter 5

# Finding Support and Information at Princess Margaret Hospital





## Finding Support and Information at Princess Margaret Hospital

Supporting you living With, Through and Beyond  
Breast Cancer.

Breast Cancer Survivorship Program

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

416.946.4501 ext. 2363

email: [survivorship@uhn.on.ca](mailto:survivorship@uhn.on.ca)

The program is here to support you and your family with, through and beyond cancer. You are considered a breast cancer survivor from the point of diagnosis. The Program will help you sort out where to start. Surviving cancer does not come with a road map. Each person's journey is unique. Often it is difficult to know where to start when you receive a diagnosis of breast cancer. Making critical decisions about your care can be very challenging while you are trying to manage all the other aspects of your life that continue regardless of your diagnosis. There are many components to the BSCP that may help you with your journey. Sign up for your individualized survivorship consultation by contacting the program.

### Patient Education Program

416.946.4501 ext. 5383

email: [patienteducationpmh@uhn.on.ca](mailto:patienteducationpmh@uhn.on.ca)

The Patient Education Program is available to you to help you find the information you are looking for at any point in your cancer experience (*Figure 18*).

*“The cancer is a shadow in my body  
compared to the lymphedema.”*

*– PMH Survivor*

## Psychosocial Oncology and Palliative Care

[www.uhn.ca/programs/psychosocial-oncology/index.asp](http://www.uhn.ca/programs/psychosocial-oncology/index.asp)

416.946.4525

email: [pop@uhn.on.ca](mailto:pop@uhn.on.ca)

At Princess Margaret Hospital, help is available for patients and family members having difficulty coping. The staff in Psychosocial Oncology and Palliative Care have expertise in providing supportive care, emotional and practical assistance through this difficult time.

We provide a range of services, including psychological and spiritual counselling, assistance with social and financial difficulties, psychiatric assessment and treatment, and pain and symptom management.

Our multidisciplinary team includes: social workers, psychiatrists, psychologists, chaplains, occupational therapists, an early childhood educator, palliative care physicians, advanced practice nurses and community clinicians.

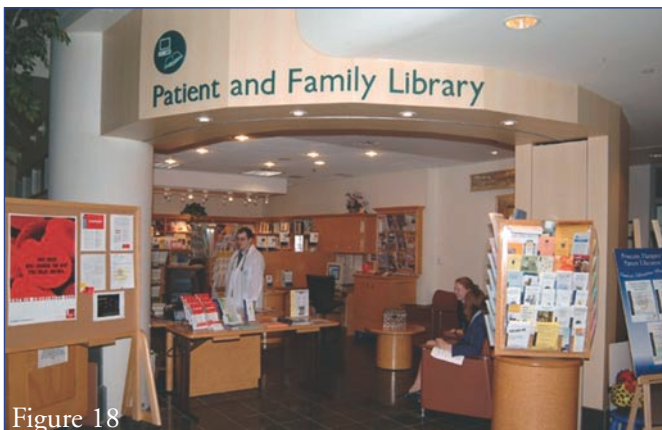


Figure 18



*“In the depth of winter,  
I finally learned that within me  
there lay an invincible summer.”*

*– Albert Camus*



Chapter 6

References and

Recommended Reading







## Recommended Reading

### Books

Lymphedema: A Breast Cancer Patient's Guide to Prevention and Healing by Jeannie Burt and Gwen White PT

Lymphedema by Robert Twyross, Karen Jenns and Jacqueline Todd

Coping with Lymphedema by Joan Swirsky, Diane Sackett Nannery

Living Beyond Breast Cancer: A Survivor's Guide for When Treatment Ends and the Rest of Your Life Begins by Maris C. Weiss, M.D. and Ellen Weiss

Lymphedema, A Breast Cancer Legacy, Breast Cancer Action Ottawa.  
[www.bcaott.ca](http://www.bcaott.ca)

### Websites

Cancer Care Ontario [http://www.cancercare.on.ca/access\\_PEBC.htm](http://www.cancercare.on.ca/access_PEBC.htm)

To print a copy [http://www.cancercare.on.ca/print/access\\_1097.htm](http://www.cancercare.on.ca/print/access_1097.htm)

Canadian Breast Cancer Research <http://www.breast.cancer.ca>

Lymphovenous Association of Ontario <http://www.lymphontario.org>

Toronto Lymphocare Centre <http://torontolymphocare.com/>

Canada Lymphovenous <http://www.lymphovenous-canada.ca>

National Lymphedema Network [www.lymphnet.org](http://www.lymphnet.org)

National Cancer Institute of Canada [www.ncic.cancer.ca](http://www.ncic.cancer.ca)

CMAJ: Clinical Practice Guidelines on Lymphedema

<http://www.cmaj.ca/cgi/content/full/164/2/191>

Survivorship booklet Getting Back on Track: Life After Treatment.  
[http://www.uhn.ca/patient/health\\_info/references/breastcancer\\_booklet.asp](http://www.uhn.ca/patient/health_info/references/breastcancer_booklet.asp)

For more information about Breast Cancer visit the Princess Margaret Hospital Web site to find out more:  
[http://www.uhn.ca/patient/health\\_info/b/breast\\_cancer](http://www.uhn.ca/patient/health_info/b/breast_cancer)

Lymphedema, What Breast Cancer Patients Need to Know  
The Thunder Bay Regional Health Sciences Centre, Regional Cancer Care has produced this new resource on lymphedema in brochure and booklet format. The information in this booklet focuses on secondary lymphedema from breast cancer treatment and deals with warning signs and symptoms, prevention, treatment, self care, complications, exercise and more. You can access the PDF format of the brochure and booklet at <http://www.ncrf.on.ca/articles/40>. For a print copy, contact the Education Program at Regional Cancer Care 1-807-684-7237.

Some of the images used in this book are courtesy of  
<http://www.btinternet.com/~fireballx15/nature/water/>.

*Many thanks to those who participated in  
The Weekend to End Breast Cancer.*





