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**Comments,  
Feedback?**

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# Patient Information

# Lymphedema



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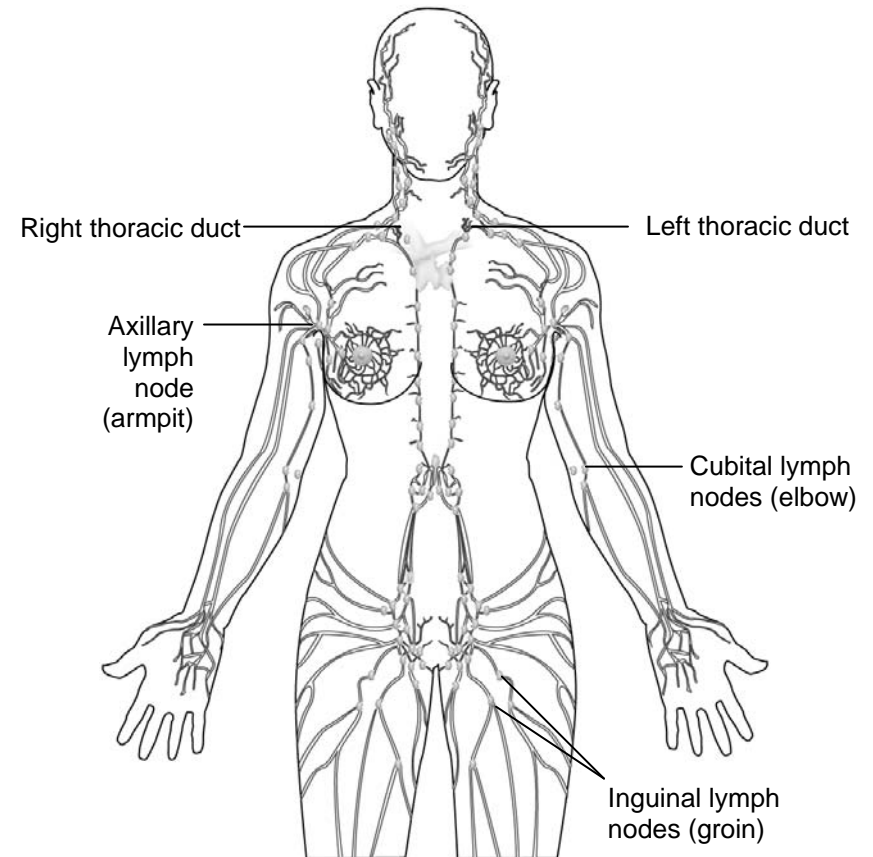




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## How does the lymphatic system work?

The lymphatic system moves fluid through ducts, vessels and thousands of bean shaped nodes in your body. The fluid is made up of water and proteins that feed the cells in your body. Lymph fluid collects in the lymph vessels, is filtered through the lymph nodes and eventually drains into the blood stream through large ducts in the chest (thoracic ducts). The proteins are recycled or leave the body as waste in the urine.



**The Lymphatic System**

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The lymphatic system works with your lungs, muscles and the circulatory system to pump blood and supply oxygen to the cells. The lungs and muscles are also important in moving lymph fluid through the body. This is why you will see that aerobic exercise (running, swimming, bicycling) is helpful in treating lymphedema.

### What does the lymphatic system do?

The lymphatic system has two functions. The main function is to help the circulatory system maintain a balance of fluid in the body. Fluids are needed to bring nutrients to, and remove waste products from, cells. Every day about three litres of fluid is absorbed by the lymphatic system and returned to the blood stream. This prevents swelling and balances the fluid in the body. Incredibly, your lymphatic system can handle up to ten times the normal amount of fluid in your body for a short period of time.

The other important function is to help defend the body from disease. When bacteria and viruses are detected in the fluid by the lymph node, it triggers special cells to remove them. This is why you might feel some swollen nodes in your neck or armpit when you have an infection or illness.

### What causes lymphedema?

Lymphedema refers to anything that slows or stops the flow of lymph fluid. When the fluid stops flowing, it collects in a part of your body like the arm, and makes it swell.

Lymphedema is classified in two ways:

Primary lymphedema refers to people born with parts of their

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lymphatic system missing or who develop a blockage due to an infection.

Secondary lymphedema happens after cancer surgery or radiation therapy. This type of lymphedema is the focus of this booklet. Secondary lymphedema can result from many things, including:

- Surgery
- Radiation therapy
- Infection
- Blood clots
- Injury
- Problems with your heart or liver
- Cancer recurrence



It is very important that your oncologist finds out the cause of the swelling *before you start any* treatment.

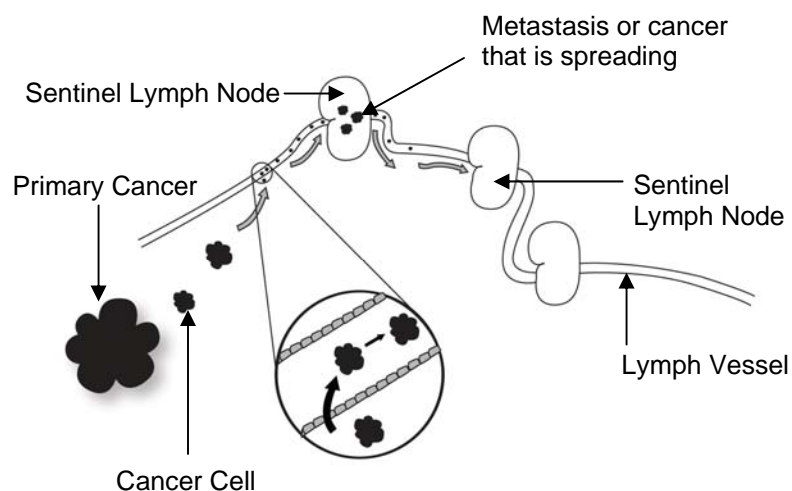
## Why can lymphedema occur after cancer surgery?

The lymphatic system is one of the first places where cancer cells may spread. For this reason, cancer surgery often includes the removal and examination of lymph nodes.

Lymph nodes act like little nets and are able to remove cancer cells from the body. However, sometimes the cancer will enter the lymph node itself and begin to grow. Surgery may be needed to see if cancer has spread to the lymph nodes. This helps find the stage of cancer and the best treatment plan.

## DID YOU KNOW?

Numbers from one to four are often used to describe the stage of cancer. The higher the number, the farther the cancer has spread. For example, in breast cancer stage four means that the cancer has spread to other organs of the body. Stage one means that it has not spread to the lymph nodes.



### Spread of Cancer through the Lymphatics

During surgery cutting tiny lymphatic vessels causes temporary swelling. Usually new connections are made and the swelling disappears within about three weeks.

Unlike the lymph vessels, lymph nodes that are removed do not regrow. The remaining lymph nodes are usually able to do the work of the removed nodes. However, some people

### Can I have breast reconstruction?

Many women want to have breast reconstruction. There are different types of breast reconstruction, including muscle flaps, tissue expanders and breast implants. Little research has been done on the incidence of lymphedema after these types of surgery. One small study suggests using a flap from the stomach is preferred over tissue expanders and breast implants in women who have lymphedema.<sup>16</sup> Talk to your surgeon about this question.

### I need to have surgery on my affected limb. What effect will this have on lymphedema?

Any surgery on the affected limb has the potential to cause or increase lymphedema but generally the swelling will lessen over time and with the use of your compression garment. At the present time there is no evidence on which to base recommendations. This is a question that should be discussed with your surgeon.

### Is laser therapy an effective treatment for lymphedema?

Laser treatment, electrical stimulation, vacuum therapy, microwave, and heat therapy have not been shown to be effective. These treatments need further study.

### Is therapeutic ultrasound an effective treatment for lymphedema?

Applying ultrasound for therapeutic purposes is **not** recommended, because it has been shown to increase the growth of tumours in animals. Ultrasound used for diagnosis is safe.

### Does lymphedema ever go away?

Swelling is normal right after surgery. For many, it decreases and never comes back. Most lymphedema develops within 2 to 4 years after treatment. There have been cases where it has occurred 30 years later. Lymphedema that develops later may come and go several times before it returns and lasts a long time. Fortunately, newer surgical techniques make lymphedema less likely.

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Good scientific studies will compare results from groups of patients. Generally, the larger the group, the better the study. Check for a reference list so that, if you choose, you can read the original research. Personal stories are interesting but may not apply to other people.

### Frequently asked questions:

#### Can lymphedema be cured?

Lymphedema can be managed but at the present time it cannot be cured.

#### Can diuretics or 'water pills' be used to treat lymphedema?

Diuretics or 'water pills' should **not** be used to treat lymphedema. If used for lymphedema, water pills can worsen swelling by causing protein to build up in the limb. Water pills are best used for other conditions that cause swelling throughout the body, not just in one arm or leg.

#### Are there any medications that can reduce lymphedema?

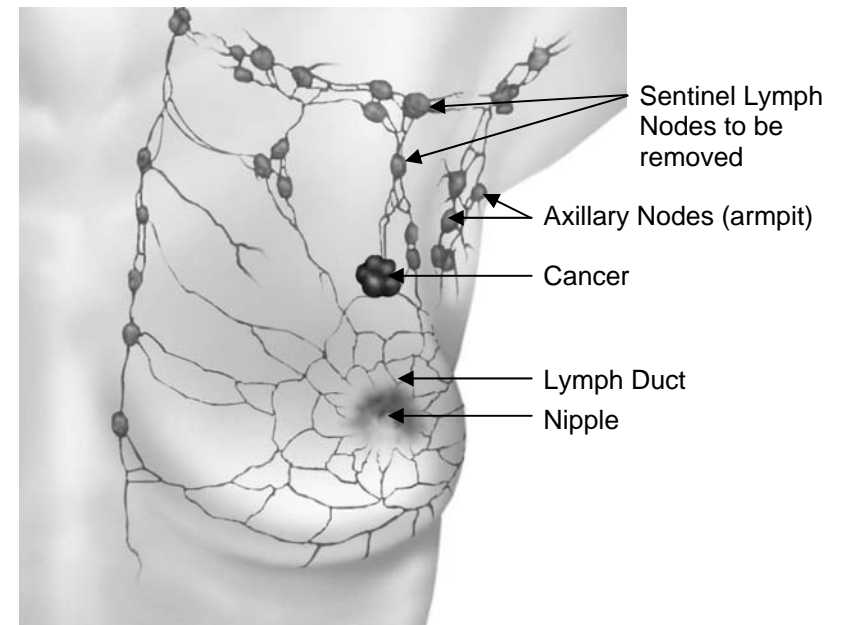
Research into products such as ointments and oral medicines is ongoing. At the present time there are no medicines that reduce lymphedema.

Several small studies have shown that selenium has a positive effect on lymphedema linked with tumours of the head and neck.<sup>8</sup> Some research using selenium for lymphedema of the arm in combination with manual lymphatic drainage (MLD) has also shown increased benefit over MLD alone. It is thought that selenium works by decreasing inflammation. Since there is no deficiency of selenium in the diet of most North Americans, selenium supplements are not needed and may even be toxic if taken in high doses.

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will develop swelling that does not go away. This may be a result of the number of nodes that are removed.

Surgeons are always improving cancer surgery and biopsies. One such method is the **sentinel node biopsy**. In this type of biopsy, the surgeon injects a special blue dye to find the "sentinel" or the closest lymph nodes to the tumor. If the sentinel nodes do not contain tumor cells, no further nodes are removed from the area. This type of biopsy has reduced the need to remove large numbers of lymph nodes for many people with breast cancer. Although sentinel node biopsy removes fewer nodes, it is still possible for lymphedema to occur. This method is not appropriate for all women.



**Sentinel Lymph Node Biopsy for Breast Cancer**

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## Why can lymphedema develop with radiation therapy?

Unlike chemotherapy, which kills tumor cells throughout the entire body, radiation therapy is used to kill tumor cells in a target area. Radiation may be used as the first treatment or after surgery and chemotherapy to prevent the cancer from returning in the area of the original cancer.

Radiation therapy may cause temporary irritation and inflammation (swelling) of the lymph vessels and nodes during or soon after treatment. This usually goes away over time. Some patients may develop chronic or long-term swelling as a result of decreased function of the lymph system in the area that was exposed to the radiation.

## Who will get lymphedema?

It is not possible to predict who will develop lymphedema. Currently, much of the research reports data from older surgical and lymph node biopsy techniques. This research suggests that most lymphedema cases will appear in the first two to three years after treatment. Some people, however, may not get lymphedema until many years later.

## What are the risks for developing lymphedema?

Lymphedema develops closest to the area treated for cancer such as the arm, chest wall, remaining breast tissue for breast cancer patients, or in the legs and the genital area for patients with cancer of the prostate, colon and other pelvic or abdominal areas. Some risk factors have been identified. These risks usually involve things that:

- a. Cause more fluid to be produced;
- b. Block fluid from leaving the treated area.

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Other good resources include :

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

The National Cancer Institute [http://www.nci.nih.gov/cancertopics/pdq/supportive\\_care/lymphedema/patient](http://www.nci.nih.gov/cancertopics/pdq/supportive_care/lymphedema/patient)

The Lymphatic Association of Australia  
[www.lymphoedema.org.au](http://www.lymphoedema.org.au)

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

## Books that may be helpful:

(all written for breast cancer patients)

*Coping with Lymphedema* by Joan Swirsky, Diane Sackett Nannery

*Lymphedema – A Breast Cancer Patient’s Guide* by Jeannie Burt and Gwen White

*Lymphedema Handbook: Prevention and Management Strategies for People with Cancer* by Ellen Carr, Linda T. Miller, Ruth McCorkle

*Lymphedema: An Information Book for Patients, Their Medical Practitioners and Health Care Workers* by Judith R. Casely-Smith and J.R. Casely-Smith

*Lymphedema: A Breast Cancer Legacy* by Breast Cancer Action  
*Ottawa*

Many cancer centres in Ontario offer special clinics that help with the diagnosis and management of lymphedema.

It can be difficult to find information about lymphedema because this condition has largely been ignored. Fortunately, researchers are doing more studies on prevention and treatment. There are websites, pamphlets and booklets that provide advice about lymphedema. When reviewing this information, you should see if the sponsors come from reliable organizations. You should also see if the recommendations are backed up by scientific data.

Sometimes people feel guilty because they fear that they did something to cause their lymphedema - especially if an activity increases swelling. Some people fear that the swelling means the cancer has returned. Most lymphedema, however, is caused by surgery and radiation given to treat the cancer and not the spread of cancer. Many people feel embarrassed when people comment on their swollen limbs or the form of compression treatment. Getting more information and talking about it can help you to cope with lymphedema.

Contact your family doctor or a Community Care Access Centre Case Manager for referral to professional counselling. The London Regional Cancer Program has staff available to help you cope with these emotions. You can refer yourself or ask a member of your care team to make the referral for you.



### Where can I find more information about lymphedema?

Organizations such as **The Lymphovenous Association of Ontario** [www.lymphontario.org/](http://www.lymphontario.org/) and **Lymphovenous Canada** [www.lymphovenous-canada.ca](http://www.lymphovenous-canada.ca) provide online education and print materials. They also have a list of lymphedema management contacts and they hold an annual conference.

Research supports that the risk of lymphedema for breast cancer patients to be between 4% (for patients who had a sentinel node biopsy) to more than 40% for patients who had a full axillary node dissection and radiation to the underarm.

The risks are divided into four categories. **It is important to note that it is unlikely that just one of these risks will cause lymphedema.**

#### 1. Disease related risks

- Large tumor size
- Large number of lymph nodes with cancer cells at diagnosis
- Blood clots in the arm or leg
- Recurrence of cancer

#### 2. Patient related risks

- Age – older patients are at higher risk
- High blood pressure
- Abnormal lymphatic systems
- Obesity

#### DID YOU KNOW?

Being overweight is one of the greatest risk factors for developing lymphedema. Many people think cancer causes weight loss but this is not the case with breast cancer. In fact, chemotherapy and hormone treatments often cause weight gain. The best way to prevent lymphedema is to reduce your weight to a healthy range when you finish your cancer treatment.

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### 3. Treatment related risks

- Wound infection after surgery
- Slanted, rather than horizontal surgical incision across the chest wall for patients who have a mastectomy, may slightly increase the risk of lymphedema
- Fluid retention at the surgical site even after the drains are removed
- Number of lymph nodes removed during surgery
- Radiation to the lymph nodes of the underarm, pelvis, and groin

### 4. Other risks

- Heat
- Injury to the affected arm or leg
- Inflammation of a blood vessel without infection
- Inflammation of a lymph vessel
- Certain activities – see section on exercise for more information

## What are the signs of lymphedema?

It is important to notice the early signs of lymphedema as the advanced symptoms are more difficult to control. **Swollen hands or feet during hot weather or first thing in the morning is usually not lymphedema.** Some of the early warning signs include:

- Indentation or “pitting” of the skin when pressure is applied that does not disappear right away when the skin is released;
- Pain, which is deep and aching;
- A feeling of heaviness in the limb;
- Clothing or jewelry that feels too tight without gaining weight;
- Gradual, but visible swelling of the arm, leg, chest wall, breast, or scrotum. It might appear and then disappear. It may become

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After the infection has been treated it can take weeks for the pinkness in the skin to completely disappear.

### **Pain:**

Pain is both an early warning sign of lymphedema and a complication. It is usually described as a deep, aching pain. Often it will come before the appearance of visible swelling or an infection. Acetaminophen (e.g., Tylenol®) or Ibuprofen (e.g., Advil®, Motrin®) can be used temporarily to reduce the pain. Many patients report relief by applying compression. Always report pain to a member of your healthcare team.

### **Fibrosis:**

Fibrosis happens when soft tissue becomes hard and feels woody. This is the result of dense scar tissue developing within the limb. Lymphedema can cause fibrosis when it is left untreated or becomes chronic over a long period of time. It is usually not reversible.

### **Angiosarcoma of the skin:**

Angiosarcoma of the skin is a very rare type of cancer that is associated with chronic lymphedema. Any open sores and purple lumps (papules) in the swollen limb should be biopsied.

## How can I cope with lymphedema?

Lymphedema is an unpleasant side effect of cancer treatment. It can seriously impact the emotional well-being of those who develop it. Living with lymphedema might make you feel frustrated, angry, sad and regretful. You may also feel embarrassed by comments made by people who notice your arm or compression garment. These are normal feelings in response to a change in your outward appearance. They become a problem when they cause isolation, depression and a reluctance to seek help for these symptoms.

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## What are the complications of lymphedema?

### Infection:

Bacteria can infect the skin through the lymph fluid. It can enter your system through breaks in the skin. Infection in the affected limb has also occurred in some people with lymphedema who have had sore throats or chest infections. The stagnant lymph fluid that collects in a limb is a great place for bacteria to grow. This is one of the reasons that you want to reduce the amount of fluid present as much as possible.

This infection is called **cellulitis**. Cellulitis is usually easily treated with antibiotics. It is important to start treatment right away. If you have two or more episodes of cellulitis in the swollen limb in a year, your doctor may want to give you a prescription for you to carry and fill at the first signs of infection. Repeated infections that are not treated right away can worsen your lymphedema.

Signs of infection include:

- Deep red discoloration of the skin that spreads;
- Pain or tenderness in the area of the redness;
- Increased temperature of the skin in the area of the redness;
- Increased swelling often just in one area of the arm or leg;
- Fever which may be felt as deep, uncontrolled shivering.



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worse over time and spread to other nearby areas in your body;

- Infection in the skin. This is called cellulitis;
  - Sudden swelling after an injury, excessive physical exertion, or airplane travel;
  - Small blisters that appear on the skin of the affected area;
  - Fluid leaking through the swollen skin;
  - Reduced movement (or loss of movement) in the arm or leg;
- Later signs can include massive swelling of the limb as shown in the photo.



## How do doctors prevent lymphedema?

Doctors who treat breast cancer try to avoid many of the risks that might cause lymphedema. Great care is taken to prevent infection during surgery. Drains are used to remove fluid from the surgical site. Newer surgical techniques reduce the need to remove large numbers of lymph nodes. Whenever possible, the radiation of lymph nodes is avoided.

## What can I do to prevent lymphedema?

Preventing lymphedema is based on two ideas:

- a. Slowing down or stopping your body's ability to make lymph fluid;
- b. Help drain lymph fluid by keeping vessels unblocked.

You may be able to prevent or delay lymphedema if you follow these guidelines. Keep in mind they are only recommendations and there may be times when following them is not possible. Many of these guidelines are based on common sense rather than research.

#### **A. Guidelines for slowing down or stopping lymph fluid from being made:**

##### **Avoid injections in the affected arm, if possible.**

Note that this guideline, although widely promoted, is not based on research. See the 'Fact' box on page 12 for more information.

Injections like the flu shot, vaccinations and intravenous drug therapy might increase the risk of inflammation or bruising. Inflammation naturally increases lymph flow. When a bruise forms, the lymph system reabsorbs the blood from the bruise. Most times, however, inflammation will not occur.

Sometimes you may need to use the affected arm for injections of contrast dye for scans. This dye does not cause inflammation and the risk of onset or worsening lymphedema is very small.

Long-term intravenous fluid infusions using a PICC line or Port-a-Cath® should also be avoided in the affected arm.

##### **Avoid injury to the affected arm or leg**

Use gloves for gardening and dish washing. Don't clip your cuticles during manicures. Instead use a cuticle oil and good hand cream. Wear an insect repellent to prevent bites. If an injury happens, wash the site right away and apply an over-the-counter antibiotic ointment to the affected area. Check the skin regularly for signs of injury or infection. Do not walk outside without shoes.

1. While laying on your back, point toes and scissor the legs in front and behind.
2. Repeat 5 times, relax.
3. Continue in the same position, laying on your back, bicycle your legs in the air.
4. Repeat 5 times, relax.

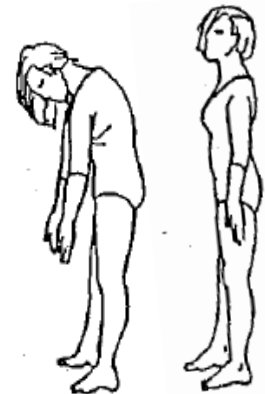


##### **Taking the knee from side to side:**

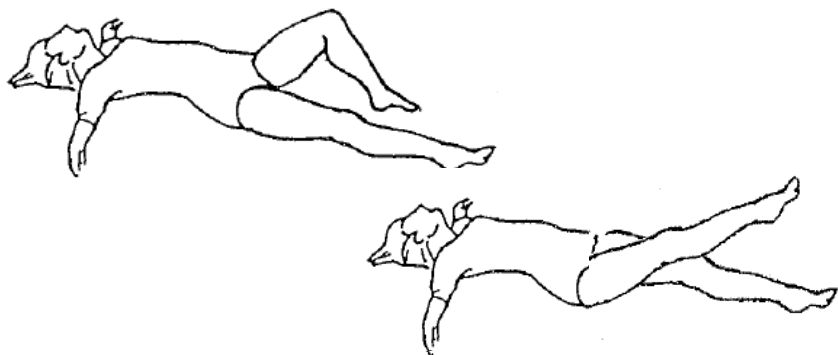
1. Bring the affected leg up so that your knee is bent and your foot is flat on the ground, adjacent to the knee of the extended leg.
2. Rock your knee as hard and as far as you can, from one side to the other, 5 times in each direction.



1. While standing, RELAX with your feet and legs up against the wall for 5 minutes
2. Bring your legs down and lie straight on the floor, or with legs slightly elevated on pillows
3. Relax for at least 15 minutes.
4. Get up slowly and stand tall.
5. Take 3 or 4 slow, deep, full breaths.

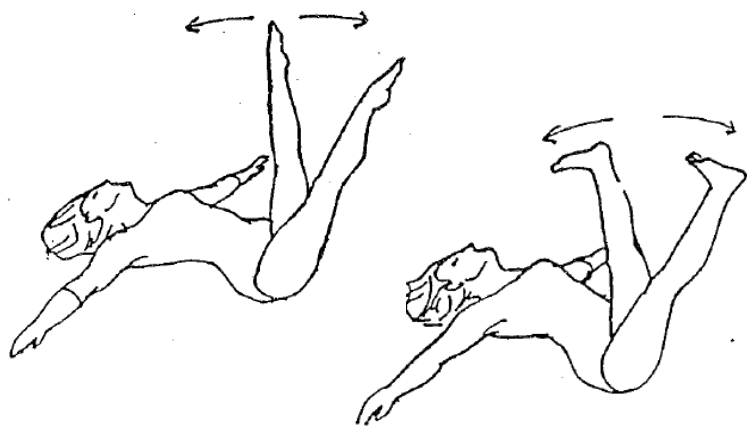


1. While lying on your back, stretch arms out to the sides of your body.
2. Bend your knees and raise one leg at a time upwards.
3. Hold for a count of 5 and then relax the leg to the ground.
4. Repeat 10 times.



#### Walking, Scissors, Bicycling in the air.

1. While laying on your back point the toes.
2. 'Walk' the legs in the air, while flexing and pointing the toes.
3. Repeat 5 times, relax.



**FACT** Women who had surgery on both breasts did not show an increased risk of lymphedema.

These women could not avoid the use of an affected arm for blood drawing and intravenous chemotherapy. Unfortunately, some sources of information about lymphedema tell patients never to use the affected arm. This has led to the refusal of important tests and life-saving treatments. There may be times when it is not possible to use the other arm. Don't panic – chances are you will not develop lymphedema.

#### Avoid excess heat to the affected arm or leg

Heat from sunbathing, hot tubs, hot baths and saunas dilates blood vessels. This allows more fluid than usual to seep into the tissues. This extra load on a struggling lymph system may cause swelling.

Wear a minimum SPF 30 sunscreen when going outdoors. Sunburn causes inflammation, which can lead to swelling.

#### Exercise

Exercise is an important part of a healthy lifestyle. Exercise helps in weight reduction and weight maintenance. **Do aerobic activities like walking and swimming, but monitor your affected limb for swelling. Stop activities that seem to cause or increase swelling.** In general, it appears that aerobic exercise is beneficial because the lungs play an important role in moving lymph fluid (see page 3). This may explain why some women have reported swelling after **non-aerobic** activities such as knitting, vacuuming or using scissors or clippers for extended periods of time.

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Recent studies have shown that exercise can reduce lymphedema by improving lymph flow.<sup>1</sup> Research data was collected from women who participated in dragon boat rowing, jogging and weight training. It was found that these activities did not cause or worsen lymphedema.<sup>6</sup>

### **Practice good skin care**

The skin is one of the first lines of defense against infection. In general, you should practice good skin care. This includes keeping the skin of the affected limb clean.

Use moisturizing lotion at bedtime. There is not one particular product that is suggested because most act in the same way. If you wear a compression garment, check with the fitter about products that are safe to use with these fabrics. Some lotions may break down the elastic.

### **B. Guidelines to help prevent the blocking of lymph vessels:**

#### **Ask for a lightweight breast prosthesis or make one yourself**

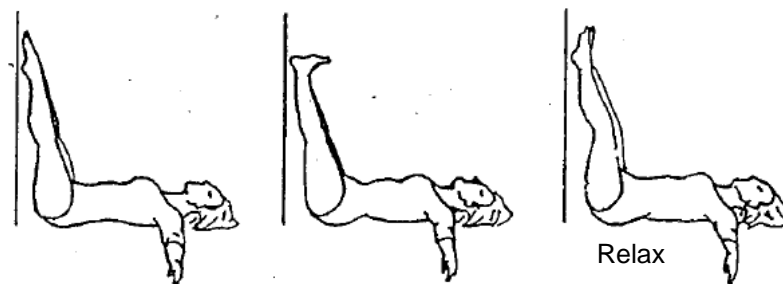
A heavy breast prosthesis in a tight fitting bra can sometimes put too much pressure on the lymphatics of the chest wall. This can cause swelling or worsen existing lymphedema. Ask for a lightweight model or make one yourself. Some women have done this by unpicking the seams of their bra and inserting fiberfill padding.

#### **Eat a balanced diet. Drink alcohol in moderation**

There is no special diet recommended. Alcohol dilates the blood vessels, which allows more fluid to leak out into the tissues. This may worsen lymphedema. Although lymphedema is a “high protein” swelling, eating a low protein diet will not help.

### **Pointing and flexing the feet:**

1. With the feet still against the wall, and the legs straight, point hard with the foot of the affected leg,
2. Flex by bringing your toes towards you and bend the ankle, pushing up with the heel. (The normal leg may remain elevated against the wall or with the knee bent and the foot on the ground.)
3. Point and flex, alternately 10 times.
4. Relax the legs against the wall.



### **Circling the ankle:**

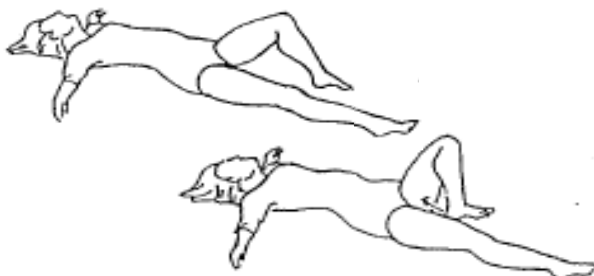
1. While lying on your back, bend both knees, placing your feet on the floor.
2. Raise the affected leg, extending it straight upwards.
3. Keeping the leg still, make a circle with the foot, big toe pointed.
4. Begin circle to the right 5 times.
5. Circle the ankle to the left 5 times.



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### **Knee bounce:**

1. Keep the non swollen leg relaxed and straight
2. Bend the other leg and lift it until the thigh is vertical and the foot is just off the ground.
3. Bounce your heel towards your buttocks.
4. Repeat for a count of 10.
5. Slowly replace the foot to the ground and stretch the leg out.



### **Stretch and flex the legs and feet:**

1. Lie with the legs against the wall.
2. Relax the legs and feet and let the knee drop to a slightly bent position.
3. Stretch the legs straight and point the toes down hard.
4. Hold, relax in starting position.
5. Repeat but instead of pointing the toes, pull them towards you, stretching the heels out.
6. Hold, relax in the starting position.
7. Repeat each exercise 5 times.



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### **Avoid blood pressure monitoring on the affected side, if possible.**

While this is often recommended, there is no proof that it causes or worsens lymphedema.

### **Avoid blocking lymphatic drainage through the lymph node-rich areas of the shoulder and groin**

Bra straps, shoulder bags, tight sleeves, jewelry or tight bands on underwear can all block lymphatic drainage. Similarly, tight bands on underwear can also reduce drainage. Putting a shoulder pad under a bra strap or purchasing bras with wide, padded straps may help.

### **Tell your health care providers that you are at risk for developing lymphedema**

You may choose to wear medical alert bracelet or carry a health information card.

### **Wear a compression garment during air travel only if you have or had swelling of the limb**

The pressure in aircraft cabins can lead to fluid seeping from blood vessels into the tissues even in people without lymphedema.

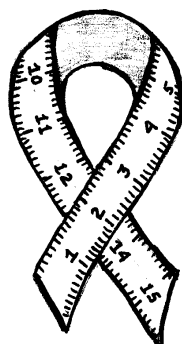
### **What do I do if I think I have lymphedema?**

If you find and treat lymphedema early, you can improve your results. Measuring the arm or leg is one way that lymphedema is diagnosed. Generally, a difference of 2 cm or more between the limbs is enough to diagnose lymphedema.

Ideally, you should measure the limb (arm or leg) before surgery (e.g., lumpectomy, mastectomy or breast reconstruction) and/or radiation therapy. Measurements that are repeated over time are the most helpful. Before you measure, please note that your dominant arm, or the arm you throw and write with, is usually bigger than your other arm by as much as 1 cm in different places. If you gain weight, **both** arms should get bigger.

#### How to measure:

You will need a pen and a flexible measuring tape (such as one used by people who sew, like tailors). If you can, find someone to help you measure your arms. The following steps will help you measure your arms at about the same place each time.



1. Bend your elbow. Mark the crease with a ball-point pen. Repeat this step with your other arm.
2. Mark a spot 10 centimetres (cm) above the crease, towards your shoulder. Repeat this step with your other arm.
3. Mark a spot 10 cm below the elbow crease, towards your hand. Repeat this step with your other arm.
4. Measure around your arm at the 10 cm mark above the right elbow. Keep the tape measure straight and level. **Do not pull tight.** Write down the measurement and repeat this step on the left arm.
5. Repeat the measurement below the elbow. Place the measuring tape at the 10 cm mark. Record the measurement for the right arm and then the left arm.

#### Buttock clenching:

1. Contract your buttocks pushing your hips upwards while keeping the rest of your body relaxed.
2. Contract slowly, hold, relax slowly, rest. Repeat 5 times.
3. Repeat knee to chest bounce as in 2.

#### Buttock contraction:

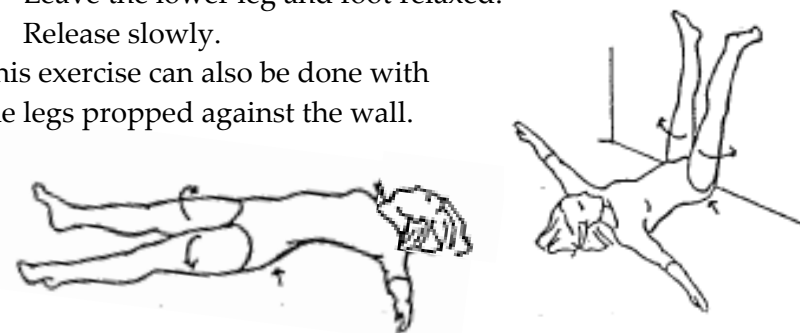
1. Raise the knee until the foot of the swollen leg is level with the other knee.
2. Clench the buttock on the side of the swollen leg only. Keep the thigh and lower leg relaxed.
3. Clench and relax 5 times.

#### Back contraction:

1. Let the swollen leg relax to the side. The knee should point away from the midline, the sole of the foot on the side of the opposite knee.
2. Clench the buttock on the swollen side and pull the leg towards the shoulder.
3. Clench and relax 5 times.

#### Bracing and turning out the thighs:

1. Relax the abdomen.
  2. Twist out the thighs from the hip to the knee by contracting the buttocks only. Do not twist out the foot.
  3. Leave the lower leg and foot relaxed.
  4. Release slowly.
- This exercise can also be done with the legs propped against the wall.



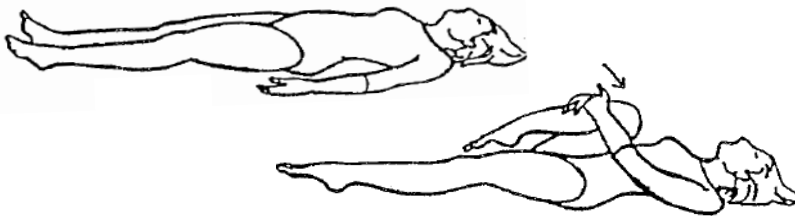
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**Relaxation:**

1. While lying on your back on the floor, relax your abdomen and pelvis, letting them sink towards the floor.
2. Focus on relaxing first the front of the thighs, then the back of the thighs, the knee, the lower leg, ankle, top of the foot, sole of the foot, and toes.
3. Slowly relax the whole foot, leg and pelvis, upper back and shoulders, chest, upper arms, and neck.
4. Finally relax the top of the head, forehead, chin, cheeks, mouth, and eyelids.
5. Rest for several minutes.

**Knee to chest:**

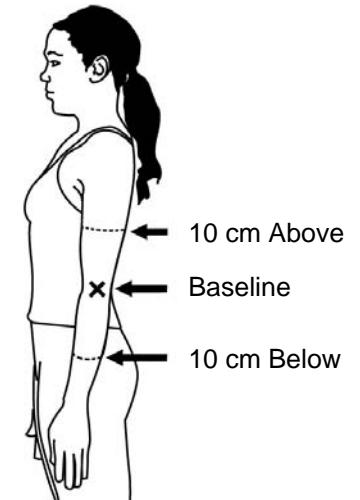
1. Bring the swollen leg up to a flexed position holding the shin with both hands keeping the other leg extended and pointed away from you.
2. Bounce the leg against the body slowly for a count of 10, lower the leg gently and relax. (Repeat with other leg if both limbs are swollen.).

**Both knees to chest:**

1. Bring both legs up to the chest, grasping the shins.
2. Gently bounce for a slow count of 10.
3. Lower both gently and relax.

6. Inspect your hands and fingers. Tight rings, fingers that are always puffy and puffiness over the back of the hand or foot can also be signs of lymphedema. Compare your elbows in a mirror.

For people with leg swelling, similar measurements can be done using the crease at knee as a starting point.

**How is lymphedema treated?**

While lymphedema cannot be cured once it has developed, it may be controlled. First, you will need to make an appointment with your family doctor to rule out a tumor. Your doctor will also check for infections and blood clots. All of these conditions need to be ruled out before treating lymphedema.

The next step is to measure “limb volume”. A physical exam of the arm, leg, abdomen, chest wall or breast may be performed. Sometimes special tests will be ordered (like a CT scan and/or ultrasound). If necessary, you may be referred back to your oncologist.

The final step is to treat the lymphedema. Treatments can improve the flow of lymph fluid and remove it from the affected limb.

## CONCERNED?

If you are concerned that you may have lymphedema, please contact your nurse at the cancer centre or family doctor for further advice. Ask for a referral to the Lymphedema Clinic at the London Regional Cancer Program.

### Treating Mild Lymphedema

#### Breathing:

Chest movement, when you are breathing deeply, has a milking effect and helps the lymph fluid flow. This is why aerobic activity is good for people with lymphedema.

#### Muscular contraction:

Muscles act like pumps and have the biggest influence on lymph flow. Compression garments used with exercise enhance the pumping action of the muscles. Evidence suggests that this will help to move the lymph fluid.

#### Elevating the limb:

Lifting your arm or leg uses gravity to help drain lymph fluid from the limbs. This is only effective if the limb is raised above the level of the heart for 45 minutes, 2 to 3 times a day.

**If lymphedema is present, compression bandages or garments must be applied afterwards to maintain the size of the limb.**

#### Skin and nail care:

Your skin needs to be healthy to keep harmful bacteria from entering your body. Skin that is stretched from the swelling of lymphedema requires good care because it is fragile.



1. Stand with feet 12 inches apart.
2. Raise up slowly onto your toes as high as you can.
3. Hold 10 to 20 seconds.
4. Repeat 5 sets, 4 times per day.
5. Rock back on your heels.

### What are the complications of lymphedema?

#### Exercises for patients with leg lymphedema

##### Equipment:

Exercise mat or a carpeted surface.

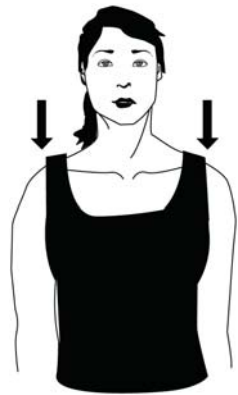
##### Instructions:

Muscle contraction stimulates the lymphatic system and assists with drainage of the swollen limb. It also helps with stiffness of the joints. It is recommended that the exercises be done twice daily allowing for 30 minutes of exercise and a 30 minute rest period afterwards. Rest with the swollen limb slightly elevated.

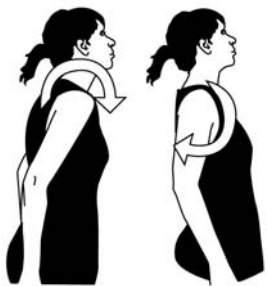
If you have lymphedema of both legs, exercise the better leg first. Rest and then repeat the whole set again for the other leg. Another option would be to do one leg in the morning and the other leg at night. If you have a back problem or problems raising your legs, do what you can lying on the floor or couch.



1. Begin with shoulders relaxed.
2. Pinch shoulders upward toward ears.
3. Hold 10 seconds.
4. Repeat 5 sets, 4 times per day.



1. Sit or stand as shown.
2. Try to push your shoulders downward as far as you can.
3. Hold 10 seconds.
4. Repeat 5 sets, 4 times per day.



1. Begin with shoulders relaxed.
2. Slowly rotate shoulders backward.
3. Repeat rotating shoulders forward.
4. Repeat 5 sets, 4 times per day.

The following guidelines will help keep your skin healthy:

- Inspect your skin everyday. Clean and cover all cuts, scratches and cracks with a bandage and apply an antibiotic cream.
- Contact your doctor right away if you see signs of infection. This includes redness, tenderness and increased swelling.
- Wash with a mild soap with a low 5.5 pH such as Dove®. Harsher soaps can dry your skin.
- Dry your skin by gently patting. Take care to dry the folds in your skin.
- Moisturize your skin daily. If you wear a compression bandage, check with the fitter to make sure that the moisturizer you use will not weaken the garment.
- Use a sunscreen with an SPF 30 or more to protect your skin from the sun.

Keeping fingernails and toenails healthy is also important. The following guidelines will help to keep your nails healthy:



- Keep your nails trimmed and cut straight across the nail.
- Do not allow your cuticles to be cut.
- Moisturize your hands and feet daily, preferably at bedtime. Make certain to apply lotion to the cuticles to prevent hangnails.
- Avoid artificial fingernails because of the increased risk of fungal infection and damage to the nail bed from filing.

### Massage:

A specialized massage pushes lymph fluid through the initial lymph ducts, which do not have valves. This stimulates a pulsing contraction, which happens when the hand stretches the skin. This movement of lymph fluid has been confirmed by dye studies. You may wish to have a consultation with a registered lymphatic drainage therapist to learn the technique for gentle self massage.

### Treating Advanced Lymphedema

While mild lymphedema may be managed by exercise and elevation more severe lymphedema requires different treatment. Reduction is the first phase where the goal is to reduce the amount of swelling. The second phase is maintenance to keep the smaller size of the arm or leg. The following therapies are currently the most effective for treating severe lymphedema.

### Compression:

Compression is the main therapy for lymphedema. This is done by using special bandages, stockings and sleeves that put pressure on the limb. If there is a lot of swelling in your arm or leg, you may be first treated with compression bandages. The goal is to move as much fluid as possible out of the limb.



**Short stretch bandages are the only type used for lymphedema.**

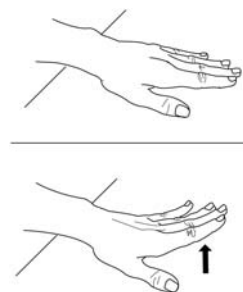
They only apply pressure with muscle movement, unlike bandages that are used for sprains.



1. Open hand and fingers fully.
2. Close hand and fingers fully.
3. Repeat 5 sets, 4 times per day.



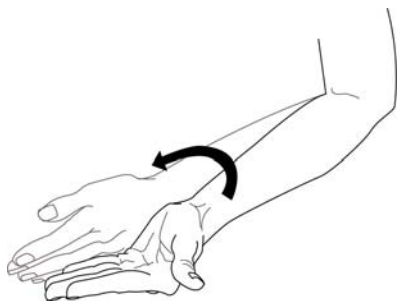
4. Repeat with arms in various positions as shown.
5. Repeat 5 sets, 4 times per day.
6. Get into the habit of doing this exercise routinely throughout the day.



1. Begin with palm of your hand flat on table.
2. Keep palm on table but lift fingers up off table.
3. Hold 10 to 20 seconds.
4. Repeat 5 sets, 4 times per day.



1. Bend affected wrist as shown.
2. Hold 10 to 20 seconds.
3. Repeat 5 sets, 4 times per day.



1. Begin with thumb facing up.
2. Turn palm downward.
3. Hold 10 to 20 seconds.
4. Repeat 5 sets, 4 times per day.



1. Hold your hands together as shown.
2. Bend the wrist until you feel a stretch.
3. Hold 10 to 20 seconds.
4. Repeat 5 sets, 4 times per day.



Bandaging is a little bulky, but it often provides relief from pain, heaviness and swelling. You will wear it day and night, removing the bandage only for bathing.

Self-bandaging is difficult for most people. A home care nurse is often asked to visit daily and, if possible, will teach a family member or friend how to apply the bandaging. If this is not possible, a nurse will continue to visit and apply the bandages. There is no charge for this

service. Two sets of bandages are also supplied to you at no charge.

It can take 2-3 weeks to reduce lymph fluid from the limb. Once smaller, a compression sleeve or stocking is specially fitted for the limb. The limb will be measured by a certified fitter who orders a custom made garment. The fitter needs a prescription from a doctor. The prescription will state the amount of compression to be applied and the type of garment. Compression garments, funded under the Assistive Devices Program (ADP), need to be ordered by a specialist, such as your surgeon or oncologist. Repeat prescriptions may be signed by your family doctor. The ADP prescription also requires the signature of a recognized authorizer. The Lymphedema Clinic can help complete this prescription for you. Family doctors can also prescribe these garments if you have private insurance benefits or if you do not wish to use the publicly funded system.



These garments can take 2-3 weeks to be delivered. During this time bandaging must be continued on a daily basis to prevent the build up of fluid. Once the garment arrives, you will put it on each morning and remove it at bedtime. If fluid comes back during the night, a lightweight sleeve or bandaging may be needed overnight.

Two sets of garments are ordered – one to wear and one to wash. These garments last 4-6 months depending on the manufacturer. After this time, the prescribed pressure lessens and swelling may come back. These garments only work if you wear them every day. Although the garments may look like they are still in good condition after 4-6 months of daily wear they will not be providing the recommended pressure. It is important to have your arm remeasured by the garment fitter prior to ordering new sleeves or stockings in case the size of the limb has changed.

The ADP funds 75% of the cost and most insurance plans cover the balance. If you do not have private insurance, and are not able to pay the rest of the cost, you can apply to the Patient Assistance Program. Please ask about these programs at LRCP.

Lightweight compression sleeves and stockings can also be bought from surgical supply companies without a prescription. These are not covered by the ADP program. They may not fit properly, especially if you are overweight or short in height.



Photo Courtesy of JUZO

Compression Sleeve

Repetitive activities, such as sweeping, knitting, vacuuming or working at a computer keyboard for long periods of time, can be a problem for some people. Wearing a compression garment and taking frequent breaks may be helpful – or you can ask another family member to do the vacuuming.

### Which exercises can help control my lymphedema?

There are educational DVDs and videos that show exercises that may help manage your symptoms.

Videos can be ordered online at:

<http://www.lymphnotes.com/article.php/id/296/>

(Checked May 25, 2011)

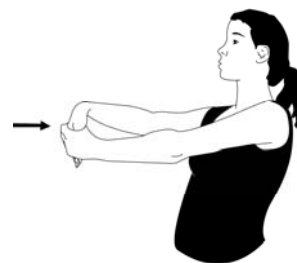
### Exercises for patients with arm lymphedema

#### Equipment:

None

#### Instructions:

An exercise program should include the following movements. These are best done sitting at a table while wearing a compression garment or bandage.



1. Hold affected wrist as shown.
2. Bend the wrist until you feel a stretch.
3. Hold 10 to 20 seconds.
4. Repeat 5 sets, 4 times per day.

Certain types of exercise are thought to be lower risk than others for developing lymphedema. It should be noted that the research into this is limited. Low risk exercises include swimming, yoga, tai chi, brisk walking and cycling. Some of the sports and exercises that are thought to be higher risk include tennis, bowling, golf and racquetball. These sports place a higher stress on your upper limbs. Jogging, stair climbing machines, downhill skiing and water skiing have a greater effect on the lower parts of your body.



This does not mean you should avoid the higher risk activities. If you were skilled at an activity before getting lymphedema, you will be at a lower risk of developing lymphedema than a beginner. Beginners need to build strength, flexibility and endurance in any new sport or exercise they start. They also need to carefully check their limbs for signs of lymphedema.

It is important to include both stretching and strengthening into your exercise program. One study showed that strenuous upper body exercise did not worsen arm lymphedema when done with stretching, strengthening and aerobic exercises. You should also space your exercise throughout the week rather than doing everything on one day.

Many patients want to work out with weights. The key is to start with lighter weights and to do deep abdominal breathing. After the exercise, see how your affected limb reacts. The deep breathing enhances the pumping effect produced in the thoracic ducts in your chest. Thoracic ducts are the major lymphatic vessels draining lymph fluids from your lower body and the upper trunk, arm and hand (see graphic on page 2).

### **Massage therapy:**

Manual lymphatic drainage (MLD) is a special type of massage therapy used in the treatment of lymphedema. It is especially helpful if you have chest wall, breast swelling, or swelling of the upper legs and buttocks. MLD sessions are about one hour long and are done daily from Monday to Friday. It is very different from a regular massage and it requires special training. In North America there are several recognized training programs including Vodder, Foldi, Harris, and Klose-Norton. If you are considering MLD, make sure the massage therapist has trained in one of these programs.

Combining MLD with compression therapy seem to produce the best results. At the end of the MLD session, the therapist will apply several layers of compression bandages. This combination of treatment is called Complete Decongestive Therapy. The reduction phase of treatment usually lasts 4-6 weeks. Patients are then fitted for a compression garment that is worn daily and, in some cases, nightly. Repeat MLD sessions may be needed to maintain the size of the limb. The number of sessions needed is based on individual needs. Some people will need weekly sessions, while others may only need once or twice a year.

The cost of MLD ranges from \$30 to \$100 per hour and there is no coverage for this therapy. Some private plans may provide limited coverage. If you have insurance, check with your insurance provider to see how often they will pay for MLD treatments.

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### Compression pumps:

Compression pumps are sometimes used to treat lymphedema. They are most often used in primary lymphedema, especially of the legs. Compression pumps come with jacket-like attachments that can fit on either the arms or legs. The recommended type is a sequential pump. This pump inflates a series of chambers to produce a milking effect. Two hours of pumping is usually suggested. When finished, either a compression bandage or compression garment is applied to prevent fluid from flowing back into the limb. If too much pressure is applied or the session is too long, fluid may collect in the shoulder causing a hard cuff.

Compression pumps are very expensive and the ADP will only cover the cost for patients with primary lymphedema. Some physiotherapy programs and surgical supply



Compression Pumps

houses have pumps available for rent. Never set the pump pressure above 40mmHg or use for longer than 2 hours.

### Weight management:

**Keeping a healthy weight is one of the best things you can do to prevent and reduce the symptoms of lymphedema.** Other benefits include heart health, joint health, and even reducing the risk of cancer returning. Many women with breast cancer are surprised that they gain weight during treatment. Weight gain

can be caused by changing activity patterns during treatment without reducing calorie intake. Hormonal therapies prescribed to reduce the recurrence of cancer can cause a modest weight gain of usually less than 5 pounds.

Weight reduction is based on a simple idea: to lose weight, you have to burn more calories than you consume. Counting calories over several



MSN

days will give you a snapshot of your actual average intake. Reducing what you eat by 500 calories per day while eating a balanced diet that includes protein, fruit and vegetables, will result in a safe one-pound per week weight loss. There are no diet restrictions specific to lymphedema prevention or treatment.

### Exercise:

Research shows that exercise is key to recovering from surgery and managing lymphedema. Your goal is to work up to a level that promotes fitness while not making the lymphedema worse. Sensations of aching or fullness might indicate stress of the lymphatic system. Check your measurements before and after activity.

Increasing exercise can also prevent weight gain. If you don't have a regular fitness routine, go out with friends for some fun activities such as dancing or skating. You can even use your family dog for some power walks! Just remember to walk with your arms up rather than swinging at your sides.