



Lymphedema: A Self Care Guide[©]

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<http://www.unccmedicalcenter.org/unccmc/hospitals-locations/profile/?id=410&searchId=42b4f017-9376-e611-8d68-2c768a4e1b84&sort=15>

The purpose of this guide is to empower you with information so that you know what signs to watch for and what you should do if you develop lymphedema. If lymphedema develops, with early detection, therapy, and excellent self-care, you can manage your lymphedema and continue to move forward to do the things you enjoy in life.

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What is the lymphatic system and how does it work?

There are two purposes of the lymphatic system: 1) To clean all the organs and tissues of the body and 2) To fight infection.

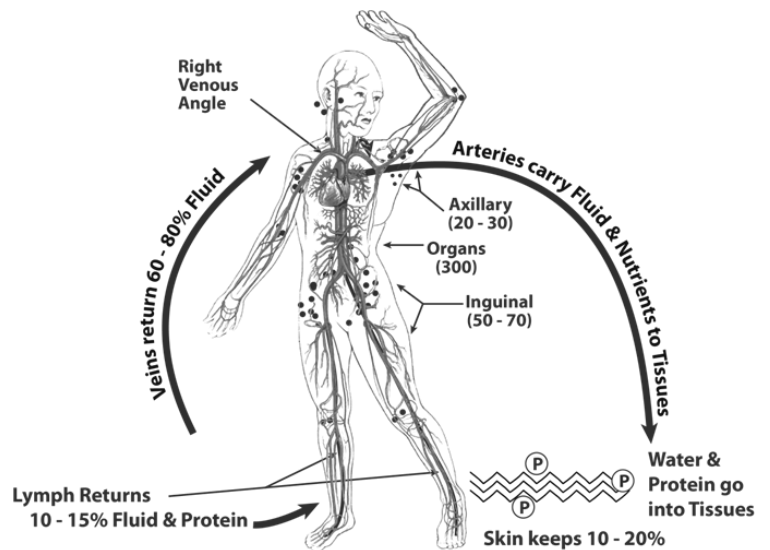
Lymphatic circulation

The heart pumps oxygen rich blood outward from the large tube like vessels called arteries, which continue to get smaller in size until they become capillaries. Fluids and nutrients leak out from the capillaries into tissues to nourish them, then are recycled and brought back into the blood circulation. The veins reabsorb 60%-80% of the fluid and the lymphatic system filters and recycles the remaining fluid and waste products. When the lymph system isn't working correctly, fluid and waste products stay in the tissues and cause increased swelling, scar tissue, and thickening of the skin.

The skin's lymphatic system consists of lymph vessels located in the skin, meeting up with regional lymph nodes located in your neck, armpits, and groin area. As the lymph vessels move fluid out of the tissues, they collect and filter waste products in the nodes, then return clean fluid to the bloodstream.

How the lymph nodes fight infection

There are 500-700 lymph nodes in the body packed tightly with cells that fight infection and filter waste products. These are dispersed throughout the body, with several hundred in the trunk and abdomen near organs, as well as hundreds in the head and neck region. The skin of the body drains into specific regional lymph nodes. Lymph fluid from the skin above the waist flows into the right and left armpits (axilla). There are about 10-40 regional lymph nodes in each axilla. The lymphatic fluid from the skin below the waist drains into the right and left groin, which hold about 50-70 regional lymph nodes. If lymph nodes are not working properly, the affected limb and trunk are at greater risk for infection because the immune system is not functioning properly in fighting foreign substances.



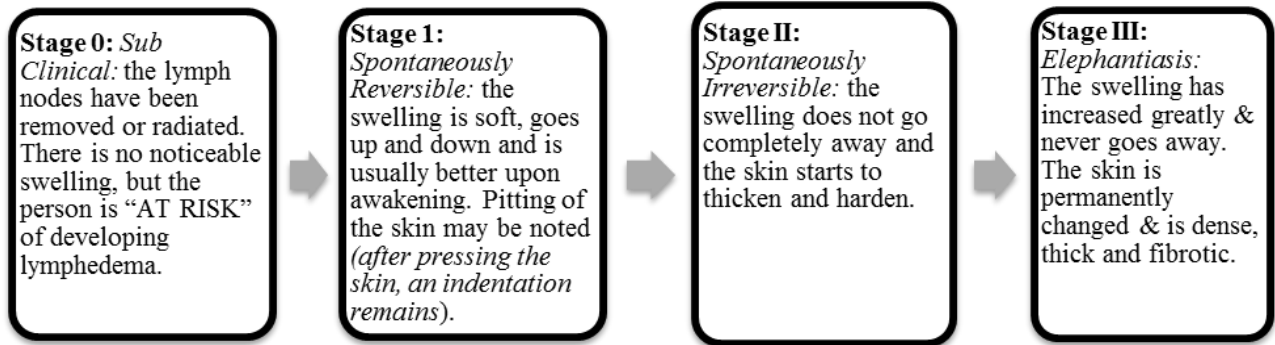
What are the risk factors of lymphedema?

It is important to note that lymphedema is not your fault. There are certain risk factors that could possibly increase your chances of developing lymphedema, but we still do not understand why someone develops lymphedema and another person with the same treatment does not. Below are some risk factors:

- Number of nodes removed, and the number with cancer
- Obesity
- Radiation and chemotherapy
- Post-operative infections or seromas
- Genetics
- Being younger age at time of diagnosis
- Hypertension
- Dominant side involved
- Axillary web syndrome or cording

How does lymphedema change over time?

Lymphedema may start immediately after surgery, or it may develop years later, or with infections or injuries to the skin.



What are the signs and symptoms of lymphedema?

- Aching, discomfort, soreness or pain in the affected area
- Feelings of heaviness, fullness, or tightness in the skin, can't see the tendons or veins in the hands or feet
- Less movement or flexibility in a joint
- Clothing, bras, underwear, jewelry, or shoes feel tight
- Swelling that fluctuates and may leave an indented spot in the skin when pressed
- Numbness/tingling in the involved limb

Who should I see if I notice swelling changes?

Ask your healthcare provider for a referral to see a lymphedema therapist who can assess your swelling. Lymphedema therapists are also physical, occupational, or massage therapists as well. “CLT” after the therapist’s name indicates that the therapist has attended at least 135 hours of post graduate courses in lymphedema care. “LANA” after the therapist’s name indicates passing a national certification exam. Check with your insurance company to see what services are covered. Find a qualified lymphedema therapist in your area by visiting these sites:

- www.lymphnotes.com
- www.lymphnet.org
- www.clt-lana.org
- www.bcreourcedirectory.org
- <http://unclineberger.org/patientcare/programs/ccsp>

Risk Reduction

How can I reduce my risk of lymphedema?

You cannot completely prevent lymphedema, but you can decrease the stress and strain on your lymphatic system by following these common sense guidelines to care for yourself, adapted from the National Lymphedema Network (NLN). See the next page for a sheet you can take with you with risk reduction tips. *The majority of these recommendations are based on knowledge of the pathophysiology and decades of clinical experience by experts in the field, but there is currently little evidence-based literature on many of these practices.*

Risk Reduction

SKIN CARE: Avoid trauma or injury *in the affected area* to reduce infection risk

- Keep skin clean & moisturized.
- Watch temperature changes:
AVOID prolonged exposure to heat (greater than 15 minutes), particularly hot tubs & saunas, placing the at risk area in water temperatures above 102 F, & exposure to extreme outdoor hot or cold when outdoors
- Protect exposed skin, use sunscreen & insect repellent
- Inform your health care providers about lymphedema, including massage therapists. When possible, no injections, acupuncture, or blood pressure cuffs on the affected limb
- No piercings or tattoos in the affected area
- Take care with shaving and nail/cuticle care. Be careful of pet scratches
- Wear gloves when doing activities that may cause skin injury (i.e. dishes, working in the garden or with tools, using chemicals)
- If scratches/punctures occur, wash skin with soap and water, apply antibiotics and observe for signs of infection (see below)
- Use an electric razor for shaving the face and neck if you have head or neck cancer treatments

ACTIVITIES/EXERCISE/LIFESTYLE:

- Gradually build up duration and intensity of exercise and take frequent rest breaks to allow for limb recovery
- Monitor at risk area during and after activity for changes in size, shape, skin texture, soreness, or heaviness
- Maintain optimal body weight. Obesity is a major lymphedema risk factor.
- Avoid carrying a heavy bag or purse on the affected side
- Drink 48 oz. of water a day to prevent dehydration and worsening of lymphedema
- For head and neck cancer patients: Avoid straining to lift objects

CLOTHING/COMPRESSION:

- Wear non-constrictive jewelry and clothing
- Compression garments should be well fitting
- Support the at-risk limb with a compression garment for strenuous activity (weight lifting, prolonged standing, running) or repetitive activity (gardening, raking, sports)
- Those with lymphedema should wear a compression garment for air travel
- Preventive garments may be helpful for the at-risk limb

ADDITIONAL PRACTICES SPECIFIC TO LEG LYMPHEDEMA:

- Avoid prolonged standing, sitting, or crossing legs
- Wear well-fitting footwear without heels



WHAT ARE THE SIGNS OF SKIN INFECTION AND WHAT SHOULD I DO?

- Fever, vomiting, chills, red and hot skin
- Itching, rash, fungal infections, or any other unusual changes on the skin of the affected body part
- Increase in swelling in the affected area
- Pain in the affected quadrant

If any of these things happen call your doctor. If your doctor is not available, go to a walk-in clinic or emergency room. Antibiotics are necessary to treat the infection and time is critical. Remove any compression and do not perform self manual lymph drainage as this could spread the infection. Compression and MLD can be restarted when the infection has been cleared by your doctor.

If You Have Lymphedema

What is the treatment for lymphedema?

Although there is no cure for lymphedema, it can be effectively managed. Treatment regimens vary, depending on the severity of swelling and condition of the skin, and may require several weeks to months of therapeutic care. Whether you are seeing a therapist, or doing self-care there are four components of treatment, **MANUAL LYMPH DRAINAGE**, **SKIN CARE**, **COMPRESSION**, and **EXERCISE**.

Treatment is performed in two phases:

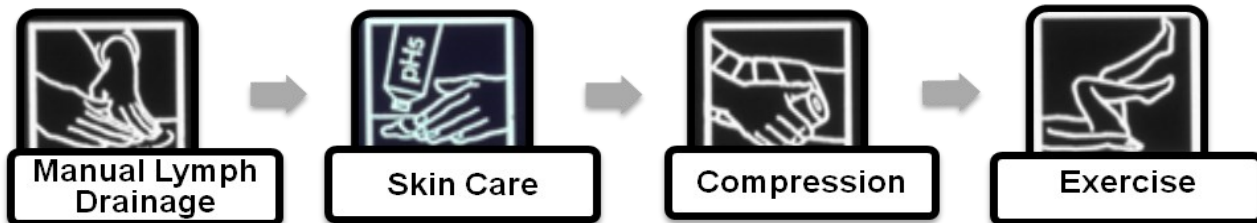
1. The intensive phase: *(You are under the care of a therapist)*

The goals of the first phase are to reduce the swelling, improve tissue health and fit proper compression garments and devices. During this time, your therapist will perform manual lymphatic drainage (MLD), use some form of compression therapy, and teach you self care techniques to include skin care and exercises to assist with lymphatic drainage. If your swelling is severe, you may require Complete Decongestive Therapy. Your therapist will give you more instructions if this type of therapy is deemed necessary.

2. The self-management phase: *(You are taking care of yourself)*

The goals of the second phase are to keep the improvements made during the intensive phase and manage the lymphedema. Once reduction in swelling is completed you are expected to be able to take care of yourself independently or with a caregiver. You may need occasional checkups should problems arise.

The Four Components of Treatment



1 MANUAL LYMPH DRAINAGE (MLD)

MLD is a very gentle, but highly effective medical massage technique, that encourages the natural circulation of the lymph through the body, following the normal lymphatic pathways to improve the overall functioning of the lymphatic system. **Manual Lymph Drainage** is a very detailed, light, slow and rhythmic massage that stimulates the flow of lymph fluid in the vessels and nodes of the lymph system. The direction and order of the MLD technique is as important as the gentle strokes. Most patients are pleasantly surprised at their body's response to this gentle technique. MLD works!

Question: *Why should I learn MLD and perform it daily?*

Answer: MLD relaxes heart rate, blood flow, and breathing rates. MLD promotes the movement of fluid and waste products out of the skin so it keeps skin from swelling or getting hard. MLD also stimulates the growth of new lymphatic capillaries.

2

SKIN CARE

The skin with lymphedema can be dry, fragile, less elastic, thickened, and prone to infection with poor healing if wounded. Keep your skin clean with a mild, fragrance free soap, and pat skin dry rather than rubbing vigorously with a towel. Moisturize with a low pH, fragrance free lotion like Eucerin or Currel daily at bedtime after self -MLD, so as not to break down the fibers of the daytime garments.

Drink six 8 ounce glasses (48 ounces) of water daily. Dehydration can trigger a response in the body to increase inflammation and thus worsen lymphedema.

Question: Why should I take care of my skin?

Answer: Taking care of your skin reduces the risk of infection and possible worsening of the lymphedema.

TAKING CARE OF SCARS:

(reprinted with permission from www.Lymphnotes.com)

Surgical Scars

Scar tissue usually heals within six weeks after surgery; however, instead of feeling soft and stretchy, a scar may still be red and tight so that it pulls and limits motions. Always check with your therapist before beginning scar massage treatment.

- Gently perform scar massage for five minutes daily. Include all scars that are limiting lymph movement. Stretches use a firm motion but should not cause an uncomfortable pulling or burning sensation. It is important to spend more time on any areas that feel “stuck.”
- Do not use lotion when massaging a scar. This causes the fingers to slide away. Apply lotion or vitamin E cream to the scar after the massage.

- **Draining the Scar**

Place your fingers on top of the scar and make very gentle circular pumping motions on the scar.

Gently work your way down the scar and feel the tissue soften. Repeat this sequence once or twice at each session. *This draining of the scar should not hurt nor should it make the scar turn red.*

- **Stretching the Scar Area**

To stretch the skin next to the scar, place two or three fingers at the beginning of the scar and stretch the skin above the scar in a parallel direction. Then move the fingers a quarter of an inch further along the scar and repeat the stretch of the adjacent tissue. Work your way along the scar. Repeat this pattern stretching the adjacent skin below the scar.

An alternative method is to follow the same pattern of finger movements using a circular motion instead of straight stretches. Work your way along the scar in a clockwise and counter clockwise fashion.

Radiation Scarring

The scarring processes after radiation can continue as long as six months after the last radiation treatment. *Massage of this affected area should not begin until at least six weeks after the last radiation treatment and when no scabs are noticeable.* Radiated tissues are delicate and the skin can break easily. Take extreme care when massaging this area. Never massage these tissues if this causes pain or increased redness of the tissues. Perform only brief massage sessions at first. As the tissues continue to heal, gradually increase the length of the massage.

- Move your fingers in a circular motion to gently stretch the skin.
- If there is a pocket of hardened tissue, very gently stretch the skin until the skin feels softer, more flexible, and is less restricting of movements.
- After the massage, apply lotion or vitamin E cream to the scar.

3

COMPRESSION THERAPY

The skin's elastic fibers and lymphatic vessels are damaged in lymphedema and the body part is always at risk for a re-accumulation of fluid. In order to prevent fluid from returning back into the skin, it is necessary to apply external compression to the swollen area. Depending on the amount of the swelling, either garments or compression bandages are worn to reduce swelling in the limb. Once the swelling is stabilized, you will need garments for daily wear. Your therapist will discuss recommended garments and arrange a fitting with a garment vendor. The garment vendor will assist you with billing and any insurance benefits.

Question: Why should I wear compression?

Answer: Compression therapy helps to reduce the hardening of the skin.
Compression therapy helps to keep the swelling out of the limb or swollen area.

How do I know that my garments fit correctly? All compression garments should be comfortable to wear and should not cause increased swelling, blisters, or redness. They should be cleaned according to manufacturer directions for proper fit, hygiene, and to ensure they last as long as possible. The fabric is woven in straight lines. After application, all the rows and seams should run up the extremity vertically. If this is not the case it is best to use rubber gloves to smooth and straighten the fabric so that the lines travel straight up the extremity.

Sleeves: Sleeves should extend from just above the wrist bone to about ½ inch to 1 inch below the armpit. It should not roll down. (see adhesive lotion below). It should not slide down the arm or bunch at the elbow. (may be too long) It should not cause the hand to swell. (may be too tight or too long)

Gloves: Fingertips of the glove typically come to the base of each nail and the wrist portion should extend above the bony portion of the wrist. Gloves are worn on top of the sleeve. There should be no gap between the sleeve and glove. Gloves should not cause the hand to swell.

Stockings: Stockings should not bunch or cut at the ankles or behind the knees, nor should they roll down or slide down the leg. (may be too long or overstretched) To correct this, the fabric simply needs to be worked down the calf and distributed evenly.

Toe Caps: Toe caps can be worn on top or below the open toe garment. The smallest toe may not need compression. It should not cause increased swelling in the toes or foot. Open toes should begin just below the toes and should not put any pressure on the foot bones.

Bras: Go to a qualified fitter for measuring. A loss or gain of 10 pounds can change your bra size. Bras should not cutoff under the armpit or at the ribs, nor cut in at the shoulders. Bras should come up as high as possible under the armpit for support in that area.

Head and Neck Garments: Should feel comfortable and not restrict breathing, swallowing or neck range of motion.

What can help me with getting my garments on and off?

The Use of Adhesive Lotion: The use of a water-soluble adhesive lotion can solve rolling or slipping of garments. To apply adhesive lotion, put the garment on and assure the proper fit of it, turn the border over and apply the roll on applicator to the skin just above the edge of the garment, allowing several minutes for the lotion to become tacky, then turn the garment border back over and adhere.

The Use of Rubber Gloves: Wearing household rubber gloves or gardening gloves makes the application of a compression garment much easier. They allow you to smooth out the fabric with minimal effort and grip the material firmly while pulling. They also protect the fabric from runs and pulls caused by fingernails or jewelry.

The Use of Slip On Aids : Various aids are available to assist with putting on and taking off garments. Your therapist will recommend one if needed.

4

EXERCISE

It is important for individuals with lymphedema to be physically fit and maintain a healthy weight, as obesity has been linked to causing and worsening lymphedema. The best type of exercise depends upon the severity and cause of the lymphedema and other co-existing medical conditions.

Question: Why should I exercise?

Answer: Exercise increases circulation and removal of lymphatic fluid from the skin. Weight control is easier, and obesity is directly linked with lymphedema.

Starting at an appropriate fitness level and gradually increasing activities while monitoring effects on swelling of the involved area are important. You may return to high intensity activities such as tennis, golf, bowling, running, and mountain biking provided you did this before the onset of lymphedema and are vigilant in monitoring your swelling.

- The three main types of exercise are aerobic, strengthening, and flexibility exercises. Additionally, lymphatic drainage exercises are simple movements that are performed in a sequence that pump fluid through lymphatic pathways and are best performed with compression.

- Aerobic exercise improves cardiovascular fitness, endurance and overall health and well-being. The goal is 30 minutes of aerobic exercise, 4-5 times a week, with a 60-65% target heart rate.
- Strength training can be beneficial for you because it will allow you to perform daily activities with less effort, thus possibly preventing injury and subsequent swelling.
- Flexibility exercises can minimize skin scarring and joint contractions that may lessen lymphatic flow.
- Pilates, Yoga, Tai Chi, Qigong, aquatic exercises, breathing exercises and relaxation are other types of exercise that have health benefits.

Follow the general safety principles listed below.

- **Always wear your compression garment if you have lymphedema. If you are “AT RISK” of lymphedema it may be beneficial to wear a compression garment.**
- Allow adequate rest intervals between sets
- Avoid constrictive clothing or weights that wrap tightly around an extremity
- Maintain good hydration
- Avoid extreme heat or overheating
- Never exercise to the point of pain

For an easy to start exercise program see page 17.

YOUR NOTES:

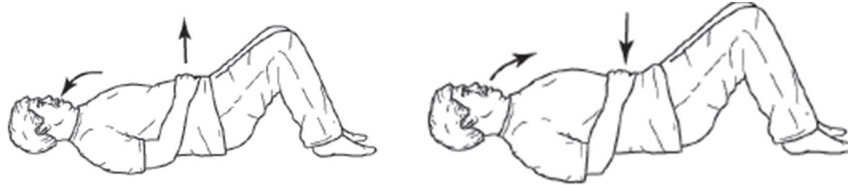
LYMPHATIC EXERCISES

Lymphatic exercises play an important role in managing lymphedema by assisting in removal of fluid throughout the tissues. They should be done in the sequence provided. Perform each exercise at least 5-10 times in a gentle manner with both limbs. If you have difficulty, let your therapist know, so that changes can be made that will allow you to perform these exercises.

EVERYONE START WITH THESE:

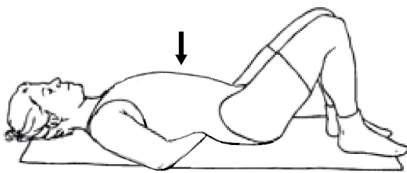
1. Abdominal breathing

Lie on your bed or floor or sit in a comfortable chair, knees slightly bent, feet on the floor, hands resting on your stomach. Take deep breaths, feeling your stomach rise as you breathe in, and breathe out slowly through your mouth. Repeat.



2. Pelvic Tilt

Lie on your back with feet slightly apart, knees bent and feet flat. Using your stomach muscles, tilt your pelvis and flatten your low back into the floor or bed. Hold for a count of 5. Release and repeat.



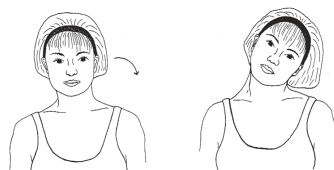
3. Neck Rotation

Inhale and turn your head slowly to one side, hold for a count of 5. Exhale and return to center, repeat to the other side. Continue on each side for 5 repetitions.



4. Head Tilt

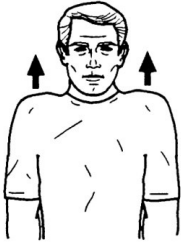
Gently bring your ear toward your shoulder, hold for 5 seconds, and bring back to center. Repeat on other side.



IF YOU HAVE ARM AND/OR HEAD/NECK LYMPHEDEMA DO THESE:

1. Shoulder Shrug

Inhale and lift both shoulders towards your ears. Exhale and return to a relaxed position.



5. Elbow Bend

Bring your hand towards your shoulder and return arm back to the side, repeat.



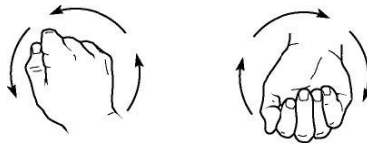
2. Shoulder Rolls

Roll shoulders back making a continuous circle.



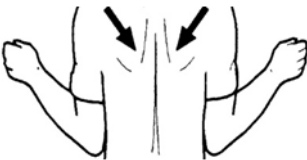
6. Wrist exercises

With your hand in a fist, make small circles with your wrist in both directions.



3. Shoulder Blade Squeeze

Squeeze shoulder blades together by pulling them backward and toward the center of your body.



7. Fist Clench

Make a fist, hold for 5 seconds, then slowly open hand and straighten fingers.

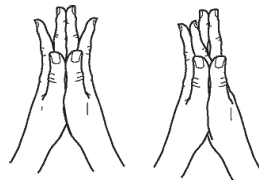
4. Isometric Hand Press

Inhale and press palms together while breathing for a count of 5, relax, and exhale.



8. Active Finger Movement

Palms together, move fingers away from each other, one pair at a time. Then move fingers together, moving from one side to the other.



9. Finish with more abdominal breathing. Then rest lying down and elevate your arm on a pillow for a few minutes.

IF YOU HAVE LEG LYMPHEDEMA DO THESE:

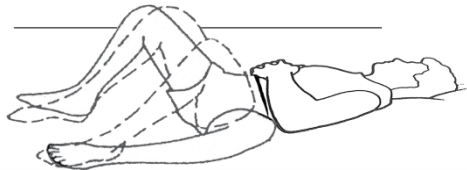
1. Heel Slide

Lie on back with both legs straight. Slide one leg up, bending knee, then slide back down. Repeat on the other leg.



2. Leg Falls

Bend both knees and keep feet flat on the floor or bed. Keep one leg in place and slowly lower your other leg out to the side. Bring back to center. Repeat on the other leg.



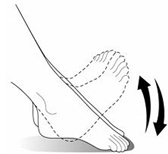
3. Leg Slides

Lie on your back with legs straight. Slide your leg out to the side and return it to the center. Keep your knees straight, kneecaps facing the ceiling. Repeat on the other leg.



4. Ankle Pumps

Move your foot up and down as if pushing a gas pedal in a car. Repeat on other foot.



5. Ankle Alphabets

Pretend to write as if your big toe had a pen.

6. Finish with abdominal breathing

WHAT ELSE CAN I DO TO HELP MY LYMPHATIC SYSTEM?

Lose weight, exercise and monitor your swelling!

1. LOSE WEIGHT

Obtaining and maintaining your proper body weight is critical in controlling lymphedema. **If you are overweight, it is important for you to lose weight.** No matter how much weight you have to lose, modest goals and a slow course will increase your chances of both losing the weight and keeping it off. **Even a small weight loss (just 10% of your current weight) will help reduce your risk.**

Calculate your BMI: (Body Mass Index):

Go to <http://www.nhlbisupport.com/bmi/> or multiply your weight in pounds by 703, and then divide by height in inches. Divide again by height in inches.

EX: 180 pound person who is 5 feet 5 inches tall:

$180 \times 703 = 126,540$
 $126,540 / 65 = 1,946$
 $1,946 / 65 = 29.9$
BMI = 29.9



Classifications:

Underweight	<18.5
Normal	18.5-24.9
Overweight	25.0-29.9
Obesity	30.0 or >
Extreme Obesity	40.0 or >

Waist Circumference Measurements:

If most of your fat is around your waist, you are at an increased risk for heart disease and diabetes: for women > 35 inches; and for men > 40 inches is a risk factor.

Nutrition Consults:

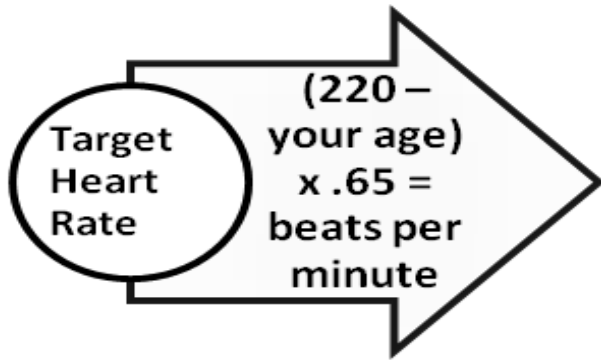
Many insurance companies now pay for visits to a nutritionist, who can help create an individualized plan for you. See a nutritionist at UNC <http://unclineberger.org/nutrition/>

2. EXERCISE

Prior to beginning any program, obtain guidelines from your doctor or therapist.

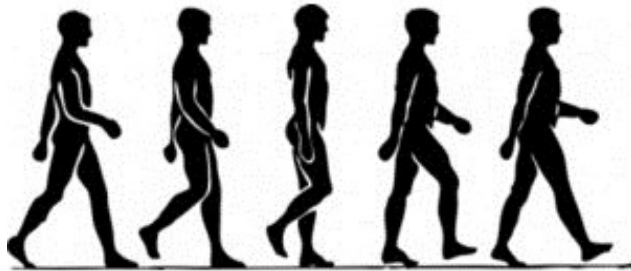
How to take your pulse and find your target heart rate:

Pulse: The number of times your heart beats in one minute. Place the tips of your index, second, and third fingers on the palm side of your inner wrist, below the base of the thumb. Or, you can place your index and second finger on your lower neck, near the windpipe. Press lightly until you feel blood pulsing beneath your fingers. Using a second hand on a clock, count the beats you feel in 10 seconds and multiply by 6 to get your heart rate. A normal resting adult heart rate is 60-100 beats per minute.



Target Heart Rate:

Certain medications for heart disease, high blood pressure, and diabetes can affect resting and target heart rates, so ask your doctor if yours is affected. Do not exercise above 85 percent of your maximum heart rate. This increases both cardiovascular and orthopedic risk and does not add any extra benefit.



Get Moving

If you don't enjoy "exercising" you can become more active by doing more everyday activities such as taking the stairs instead of the elevator, taking walking breaks during work and spending less time watching television or working on the computer. Once you are comfortable at this level, try adding more moderate activities, such as hiking, golf, light weight lifting, gardening, dancing, and bicycling. If you need structured group activities, try joining community recreational programs, the YMCA or a health club, or get a walking buddy. You can find a variety of activities for all fitness levels and budgets.

Walking is a popular activity because it is safe and convenient. On the next page is a walking program to help you get started. Use good posture and take long, easy strides. Bend your elbows and swing your arms. If you have arm lymphedema, you may want to use a walking stick to keep the arm raised higher with each arm swing. Be sure to wear appropriate footwear. Get fitted for good walking shoes that address any foot issues you may have. Wear appropriate outdoor gear to match the weather and hydrate well before and after your walk. Don't like to walk outside? Join a gym and use the treadmill or become a mall walker.

A Sample Walking Program

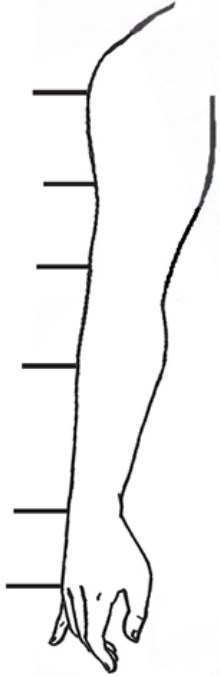
(adapted from U.S. Department of Health and Human Services, National Institute of Health)

	Warm Up	Exercising	Cool Down	Total Time
Week 1				
Session A	Walk 5 min	Brisk walk 5 min	Slow walk 5 min	15 min
Session B	Repeat as above			
Session C	Repeat as above			
Continue with at least three exercise sessions during each week of the program				
Week 2	Walk 5 min	Brisk walk 7 min	Walk 5 min	17 min
Week 3	Walk 5 min	Brisk walk 9 min	Walk 5 min	19 min
Week 4	Walk 5 min	Brisk walk 11 min	Walk 5 min	21 min
Week 5	Walk 5 min	Brisk walk 13 min	Walk 5 min	23 min
Week 6	Walk 5 min	Brisk walk 15 min	Walk 5 min	25 min
Week 7	Walk 5 min	Brisk walk 18 min	Walk 5 min	28 min
Week 8	Walk 5 min	Brisk walk 20 min	Walk 5 min	30 min
Week 9	Walk 5 min	Brisk walk 23 min	Walk 5 min	33 min
Week 10	Walk 5 min	Brisk walk 26 min	Walk 5 min	36 min
Week 11	Walk 5 min	Brisk walk 28 min	Walk 5 min	38 min
Week 12	Walk 5 min	Brisk walk 30 min	Walk 5 min	40 min
Week 13 on:	Gradually increase your brisk walking time to 30-60 minutes, three to four times a week.			

YOUR NOTES:

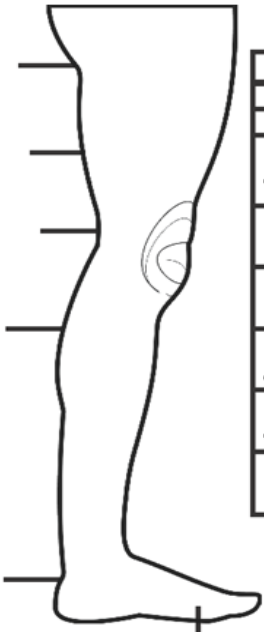
3. MONITOR SWELLING CHANGES

Make a mark at your wrist, the mid forearm, the mid upper arm and near the armpit. Take a measurement in centimeters from the nailbed of the middle finger to the marks at the wrist, mid forearm, mid upper arm and armpit, and record these in the area measured box. Now make marks on your other arm at the exact same spots. Measure the circumferences at each mark and record it. Compare sides. Any difference greater than 2 centimeters should be addressed through compression and self-treatment.



Area Measured	Date		Date		Date		Date		Date		Date		Date	
	R	L	R	L	R	L	R	L	R	L	R	L	R	L
Armpit ___cm from nailbed														
Mid upper arm ___cm from nailbed														
Elbow crease														
Mid forearm ___cm from nailbed														
Wrist ___cm from nailbed														
Palm crease														

Make a mark at ankle, the mid lower leg, the mid upper leg, and near the groin. Take a measurement in centimeters from the heel to the marks at the ankle, mid lower leg, mid upper leg, and groin, and record these in the area measured box. Now make marks on your other leg at the exact same spots. Measure the circumferences at each mark and record it. Compare sides. Any difference greater than 2 centimeters should be addressed through compression and self-treatment.



Area Measured	Date		Date		Date		Date		Date		Date		Date	
	R	L	R	L	R	L	R	L	R	L	R	L	R	L
Groin/upper thigh ___cm from heel														
Mid upper leg ___cm from heel														
Knee crease														
Widest part of calf ___cm from heel														
Ankle ___cm from heel														
Base of toes														

Troubleshooting for Increased Swelling?

First of all, make sure you're not experiencing a life-threatening issue, such as skin infection or blood clot.



Seek medical attention immediately for these:

Possible Skin Infection: Symptoms would include swelling, redness, itching, blisters, a fever, fungus, etc. If you suspect that you have an infection, contact your doctor for antibiotics. Remove all compression and do not perform MLD until cleared by your doctor.

Possible Blood Clot: Symptoms would include shortness of breath, swelling, or pain that is not usual for you. Contact your doctor, as this may be a blood clot. Remove all compression and do not perform MLD until cleared by your doctor.

If skin infection and blood clots are not the issue, here are some troubleshooting strategies:

- Am I wearing my compression appropriately? Daytime compression during the day, night-time garments during sleeping.
- Has my affected area been stressed with an injury, bug bite, etc? See skin care instructions.
- Are my garments still working correctly? Garments need replacements every 3-6 months because they become stretched out.
- Have I tried wrapping the involved limb for 3-5 days in a row (24 hours a day)?
- Have I increased my self- MLD to 3-4 times a day?
- Am I doing all my exercises?
- Am I eating a healthy, low-salt, low-fat diet, and drinking 48 ounces of water? Have I gained weight?
- Have I changed or added a new medication (ask your pharmacist if they cause swelling or inflammation)?
- Is it hot outside? Summer time heat increases swelling so stay cool and drink plenty of liquids.

If you have tried the strategies above and are still having problems, contact your therapist.

We hope this booklet helps you to understand that lymphedema can be successfully managed with early detection and treatment. If you develop lymphedema, you can still lead an active healthy life doing what you enjoy.

LYMPHEDEMA RESOURCES

UNC HEALTHCARE

NC Cancer Hospital: UNC Lineberger Comprehensive Cancer Center Comprehensive Cancer Support Program

Provides individual and group support, symptom management, pain control, educational materials and programs, nutritional consults, survivorship programs, massage, yoga, acupuncture, and referrals for additional support services to support you through your cancer journey. <http://unclineberger.org/ccsp>

Center for Rehabilitation Care

Lymphedema Services
1807 North Fordham Blvd
Chapel Hill, NC 27514
984-974-9700

Finding Qualified Lymphedema Therapists:

- www.lymphnotes.com
- www.lymphnet.org
- www.clt-lana.org
- www.bcreourcedirectory.org
- <http://unclineberger.org/patientcare/programs/ccsp>

Lymphedema Websites

Many websites change links. You may need to search around the website for specific links. Visit <http://unclineberger.org/ccsp> for the most up to date resources.

- **National Lymphedema Network (NLN):** Lists support groups, therapists and treatment centers, funding for garments. <http://www.lymphnet.org/>
- **Lymphatic Research Foundation:** Information on clinical trials and fundraising for research. <http://www.lymphaticresearch.org/>
- **Lymph Notes:** Extensive site providing lymphedema education and online forums <http://www.lymphnotes.com/>
- **Lymphedema People:** A site for people with lymphedema by people with lymphedema. <http://www.lymphedemapeople.com/>
- **Circle of Hope Lymphedema Foundation:** <http://www.lymphedemacircleofhope.org/>
- **Lighthouse Lymphedema Network:** <http://www.lymphedemalighthouse.org/>
- **Lymphology Association of North America (LANA):** Includes list of certified lymphedema therapists. <http://www.clt-lana.org/>
- **Excellent YouTube video about lymphedema**
http://www.youtube.com/watch?v=-6WBF4FN98s&feature=player_embedded
- **Children with Lymphedema:** Online support group for parents, families and caregivers of children with lymphedema <http://health.groups.yahoo.com/group/childrenwithlymphedema/>

Cancer Related Lymphedema

- **CancerCare** Sponsors limited financial assistance for cancer patients. Funds are for home care, child care, transportation, pain medications, chemotherapy, radiation and lymphedema services. There are income guidelines. 800.813.HOPE (4673) <http://www.cancercare.org/>

Breast Cancer Related Lymphedema Resources

- **Living Beyond Breast Cancer's Guide to Understanding Lymphedema** <http://www.lbbc.org/LBBC-Library?SearchText=lymphedema>
- **Breast Cancer Resource Directory:** <http://bcresourcedirectory.org/>
- **Información Para Las Mujeres Latinas:** http://bcresourcedirectory.org/directory/05-hispanic_american.htm
- **New Life After Cancer:** Promoting survivorship after breast cancer. <http://www.newlifeaftercancer.org/>
- **Breastcancer.org**
- **Sisters Network, Inc:** national and NC chapter programs providing support for African-American women. <http://sistersnetworkinc.org/>
- **Susan G. Komen NC Triangle Affiliate:** <http://www.komennctriangle.org/>
- **Fleet Feet Sports,** Carrboro, NC: local resource for mastectomy sports bras and athletic shoes. <http://www.fleetfeetcarrboro.com/>

Exercise Resources

UNC-Chapel Hill Exercise Resources:

- **Get Real and Heel:** Get REAL & HEEL an exercise program for patients with all cancer types. They develop an individualized plan that helps each participant manage cancer treatment-related symptoms and increase fitness. Because of grant support, this program is currently provided to individuals free of charge. Please visit Get REAL & HEEL or call 919-962-1222. <http://getrealandheel.unc.edu/>
- **Cancer Transitions** is a class series to help cancer survivors and their caregivers make the transition from active treatment to post-treatment care. Cancer Transitions is offered quarterly at Carolina Pointe II. Meet other survivors, get your questions answered and learn how to move forward and positively impact your life. Expert panelists including physicians, nutritionists, nurses and fitness experts will discuss topics such as: Get Back to Wellness, Healthy Eating Post-Treatment, Medical Care and Surveillance, Physical Activity, and Emotional Health and Wellbeing. You will learn about exercise tailored to each participant's abilities, training in relaxation and stress management and tips for nutritious eating. <http://unclineberger.org/ccsp>
- **The LiveFit Cancer Exercise Program** is a 10-week exercise program for cancer survivors who have been treated within the last year. The program is limited to 6-12 participants. Classes will be held at the UNC Wellness Center at Meadowmont. Each exercise session will consist of a small group routine that varies each week. Progressive exercise will include, but is not limited to: Cardio Machines, Strength Training, Functional Training, Core Training, and Flexibility/Range of Motion Exercises (for example: Aqua Aerobics, Yoga, Low-impact Aerobics, and Mindfulness/Meditation Training). For more information, please contact the UNC Wellness Center at Meadowmont at 919-966-5500 or visit www.uncwellness.com.

General Exercise Resources:

- **LIVESTRONG at the YMCA** LIVESTRONG at the YMCA is a twelve-week, small group program designed for adult cancer survivors. The program is conducted outside of medical facilities to emphasize that LIVESTRONG at the YMCA is about health, not disease. Call your local YMCA and see if they offer a free program with LIVESTRONG or visit <http://www.livestrong.org/what-we-do/our-actions/programs-partnerships/livestrong-at-the-ymca/livestrong-ymca-locations/>
- **American Cancer Society: Eat Healthy and Get Active**
Find information on getting started and making exercise work for you.
<http://www.cancer.org/healthy/eathealthygetactive/index>
- **Couch to 5K** is a program that's been designed to get just about anyone from the couch to running 5 kilometers or 30 minutes in just 9 weeks. <http://www.c25k.com/>
- **If you have a smart phone:** There are numerous phone apps, such as LoseIt!, and MyFitness Pal to help you monitor your nutrition and exercise.

Finding Financial Help for Lymphedema

- **UNC Healthcare:**
 - Financial counselor 919-966-6213 CRC: Francisco Gonzalez 984-974-9712
 - Charity Care: 919-966-3425
- **1sourceapp.org:** One free compression sleeve for breast cancer related lymphedema, 225 Cedar Hill Street, Suite 20, Marlborough, MA 01752, (508) 630-2242
- **1 in 9:** The mission of 1in9 is to offer aid and comfort to breast cancer patients and their families facing financial crisis, by providing assistance for their unique non-medical needs that might prevent them from receiving or completing their treatment. 1in9, 8024 Glenwood Ave, Suite 200, Raleigh, North Carolina 27612. Call: 1-919-582-9798. Email: contact@1in9.com, or visit website at <http://www.1in9.com/>
- **CancerCare:** CancerCare sometimes has funding from Avon and Komen and list lymphedema as an area they can help with. <http://www.cancercare.org/financial/information>
- **Lymphedema Resources, Inc:** PO Box 1115, Estero FL33929
<http://lymphedemaresources.org/garment-fund.htm/>
- **Lymphedema Treatment Act:** This federal bill aims to improve insurance coverage for the compression supplies used in the treatment of lymphedema from any cause. To learn more about this bill and how you can support its passage visit <http://LymphedemaTreatmentAct.org>.
- **Lighthouse Lymphedema:** One time assistance for breast cancer related bandages/garments
<http://lymphedematreatmentact.org/>
- **Patient Advocate Foundation:** Scroll down under the Financial Aid Fund Division and you'll see a PAF/Komen grant. They provide a one-time \$300 grant. It specifically mentions lymphedema care.
<http://www.patientadvocate.org/news.php?p=971>
- **Solaris:** One free Tribute Night time garment for children (888)-918-9180 <http://www.solarismed.com>
- **UNC Cancer Patient Fund:** Limited funds, such as Stomp the Monster, available to assist patients with garment needs, Cindy Rogers, JD Patient Assistance Coordinator, Comprehensive Cancer Support Program (984)- 974-8112 cdrogers@email.unc.edu

Nutrition Info

- **UNC's Nutrition Info:** The Outpatient Oncology Nutrition Program provides individual nutrition counseling from Jennifer Spring, RD, LDN and Mandy Holliday, MPH, RD, LDN, CNSC. As registered dietitians, they understand many of the common challenges related to treatment for and recovery from cancer. The program also offers nutrition classes for patients and families and educational programs related to nutrition and cancer. <http://unclineberger.org/nutrition/>
- **UNC Weight Loss Programs**
The Weight Research Program is a behavioral research lab at the University of North Carolina at Chapel Hill (UNC). They are affiliated with the UNC School of Public Health and the Lineberger Comprehensive Cancer Center. The research program applies innovative and effective techniques for weight loss and weight maintenance. The staff includes psychologists, registered dietitians, health behavior specialists and exercise physiologists. <http://uncweightresearch.org/>
- **AICR: American Institute for Cancer Research**
This is a great site for information about diet, how to get started, recipes, and more. <http://www.aicr.org/reduce-your-cancer-risk/weight/>
- **American Cancer Society Nutrition Info:**
Good health starts with good nutrition. Here you'll find tips and recipes to help you and your family make healthy food choices. <http://www.cancer.org/healthy/eathealthygetactive/eathealthy/index>

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