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Lymphedema: A Brief Self Care Guide[©]

Condensed Version

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<http://unclineberger.org/ccsp>

The purpose of this guide is to help you learn what you can do to reduce your risks of lymphedema, how to detect it, and what to do if you develop it so that you can keep doing the things you enjoy in life!

Keep in mind, if you're experiencing lymphedema and any challenges because of it, there are resources to help!

The resource section of this booklet has local, statewide, and national resources listed.

It can also be helpful to talk to other people experiencing the same thing as you, whether it is a phone call, a support group, online, or a passing conversation.

Your local health providers may know about other resources in your area.

Lymphedema is a buildup of fluid in the skin of an arm or leg or in your chest, breast, head or neck. Normally, your body carries a clear fluid called “lymph” through a special network of vessels and nodes. This network is called your lymphatic system. Lymphedema happens when damage occurs to this system and lymph cannot move through the body. This can happen after cancer treatments, including surgery and radiation. If the lymph fluid cannot be moved through your body, it can cause swelling in that area.

What causes lymphedema?

Most lymph vessels are just under the skin. Anything that damages the skin can also harm the lymph vessels. Some cancer treatments, such as having surgery to remove the lymph nodes or having radiation treatments to the skin, can cause lymphedema.

Some people are born with problems that damage the lymphatic system. This usually happens in the legs, but can be in other parts as well.

What are the symptoms of lymphedema?

Lymphedema can happen in the first few months of cancer treatments or it may happen months to years later. The affected area may have the following symptoms:

- Swelling
- Heaviness, aching or pain
- Less flexibility
- Weakness
- Tightness of the skin
- Clothes or jewelry may feel tighter

What are the stages of lymphedema?

Stage 0: The lymph nodes have been removed with surgery or the area has been treated with radiation. There is no swelling but the person is at risk for having lymphedema.

Stage 1: There is some swelling that comes and goes. The area feels soft but there may also be “pitting”. This when the skin is pressed with a finger and in indentation remains in the skin.

Stage 2: The swelling is present all the time and does not ever go completely away. The skin starts to thicken and feel hard.

Stage 3: There is a lot of swelling that never goes away. The skin feels thick and hard all the time.

Can I prevent lymphedema?

There is no way to completely prevent lymphedema. You can lower your chances of having lymphedema though. Follow these steps to care for yourself at home:

Skin Care

- Take good care of your skin. Keep it clean and moisturized. Clean any cuts, scrapes, or blisters and apply an antibiotic ointment and a band aid. Be careful with shaving and nail care.
- Wear sunscreen and bug spray when you are outside to protect your skin.
- Avoid extreme hot or cold temperatures as they can increase your swelling. Do not stay in hot tubs or saunas for more than 15 minutes and not hotter than 102° F.
- Avoid tight clothing, undergarments and jewelry.
- Do not have any shots or blood draws in the affected area. Also, do not let anyone take your blood pressure on the affected side. Do not get any piercing or tattoos in the area.
- You may need to wear a compression sleeve or garment for some activities. Talk to your lymphedema therapist to find out what kind of garment you may need.

Diet and Exercise

- One of the most important things you can do is to keep a healthy weight. Being overweight increases your chances of having lymphedema.
- Exercise is important. Be sure to follow the guidelines given to you by your UNC Cancer Care team before starting an exercise program.
- Eat a low salt, low fat diet. Drink at least 6 to 8 glasses of water each day.

What is a lymphedema therapist?

If you notice any signs of lymphedema, talk with your UNC Health Care team right away. A member of your care team will give you a referral to see a lymphedema therapist. It is important for you to see a certified lymphedema therapist for your lymphedema treatment. Your therapist will decide the best treatment for you. A lymphedema therapist with the initials CLT (certified lymphedema therapist) has special training in lymphedema care. The initials “LANA” means the therapist has passed a national certification exam. These internet resources can help you find a therapist near you:

www.lymphnotes.com

www.lymphnet.org

www.clt-lana.org

www.bcreourcedirectory.org

How is lymphedema treated?

There is no cure for lymphedema, but it can be managed. Treatment for lymphedema is done in 2 phases:

1. The **intensive phase** — During this phase you will work closely with a lymphedema therapist to control your lymphedema. You will also be taught how to manage your lymphedema at home.
2. The **self-management phase** — During this phase, you will be able to take care of yourself. You may have occasional check-ups with your therapist.

The number of visits you have will depend on how much swelling or skin changes you have. Both of the phases have 4 main parts:

Manual Lymph Drainage

This is a gentle treatment where your lymphedema therapist uses light strokes on the skin of the affected area to help move the fluid. A series of these treatments can decrease your swelling. Your therapist will also show you how to do this at home.

Compression Therapy

Special compression wraps or sleeves can help you to prevent and manage swelling in the area. Compression therapy can also help to soften the skin. You will be fitted with compression garments that are made just for you during the self management phase.

Skin Care

The skin in the affected area can be dry and thick. If your skin becomes cracked or torn, you could get an infection. It is hard for your body to heal damaged skin when you have lymphedema. Keep your skin clean and dry. Use a mild, fragrance free soap and pat rather than rub your skin dry after bathing. Use a cream or lotion, such as Eucerin® or Curel®, every day at bedtime when you are doing your manual lymph drainage.

Diet and Exercise

Exercise helps your body remove lymph fluid and also helps you be healthy. It is important to be at a normal weight and be in good shape. Talk with your care team about a diet and exercise plan that is right for you.

Follow these safety rules while you exercise:

1. Wear your compression garment while exercising, if you have one.
2. Do not wear tight clothing or weights that wrap tightly around you.
3. Drink plenty of fluids.
4. Never exercise to the point of pain.
5. Do not let yourself get overheated while exercising.

Complete Decongestive Therapy (CDT)

If you have swelling or skin changes, your lymphedema therapist may recommend **Complete Decongestive Therapy (CDT)**. You must check with your insurance company to find out if this service is covered before starting your treatment. This treatment will include:

Evaluation: You will start with a one hour session with your lymphedema therapist. Your therapist will take a complete history from you and ask you questions about your lymphedema. They will also measure the area and take photos of the swelling and skin changes. After your evaluation, your therapist will talk with you about a plan of care. If you need a compression garment or wrap, they will talk with you about that as well.

Education: Your treatment will include 2 to 3 visits to teach you and/or a caregiver how to do manual lymphatic drainage and properly wear your compression wrap. Your therapist will also talk with you about exercises and skin care. Bring any compression garments or wraps to every appointment.

During the Intensive Phase of Therapy:

- During this phase, most people have 1 to 1 1/2 hour treatments 4 to 5 times a week. How many weeks you need therapy will depend on how much swelling or skin hardness you have.
- The compression wraps must stay on 23 hours per day and are only removed for your therapy visit. Cover your compression wrap with a plastic bag while showering or take sponge baths. Cast cover bags can be found at local medical supply stores.
- Choose loose fitting clothing during this phase. The wraps can increase the size of your arm or leg and your regular clothes may not fit.
- You may drive.
- You may also work, depending on your job. Talk with your employer about the dress code and the need to move around and stretch during the work day.

During the Self-Management Phase of Therapy:

- The swollen area is measured weekly. Once the size of the affected arm or leg becomes stable, your therapist will fit you for a compression garment.
- It takes 1 to 2 weeks for your garment to be made.
- You must check with your insurance company to find out if this is covered under your plan.
- Prices range from \$75 to several hundred dollars.
- Your garment will need to be replaced every 3 to 6 months.
- You will still have occasional treatments with your therapist, usually 1 to 3 a week for a few weeks and then less often.

Compression Garments

All compression garments should be comfortable to wear. They should not cause swelling, blisters or redness. Your garment will come with directions for how to clean them. There are many different types of compression garments. Here are some tips for wearing each one.

Sleeves: Sleeves should go from just above the wrist to about 1/2 to 1 inch below the armpit. It should not roll down or slide down and bunch at the elbow. It should not cause your hand to swell.

Gloves: The fingertips of the glove usually comes to the base of each nail. The wrist part of the glove should go above the bony portion of the wrist . Gloves are worn on top of the sleeve. There should not be a gap between the sleeve and the glove. Gloves should not cause your hand to swell.

Stockings: Stockings should not bunch or cut at the ankles or behind the knees. They should not roll down or slide down the leg. Open toe stockings should begin just below the toes and should not put any pressure on the foot bones.

Toe Caps: Toe caps can be worn on top or below the open toe garment. The smallest toe may not need compression. Toe caps should not cause increased swelling in the toes or foot.

Bras: You will need your bra fitted. A loss or gain of 10 pounds can change your bra size Bras should not cut under the armpit or the ribs and should not cut in on the shoulders. Bras should come up as high as possible under the armpit for support in that area.

Tips for putting on and taking off your compression garment:

Adhesive Lotion: You can use a water soluble adhesive lotion to help garments stay in place. To use this lotion, put the garment on and be sure it is properly fitted. Turn the border over and apply the roll-on applicator to the skin just above the edge of the garment. Allow several minutes for the lotion to become tacky. Then turn the garment border back over and press in place.

Rubber Gloves: Wearing household rubber gloves can make it easier for you to put on your compression garment. They will make it easier to smooth out the fabric and grip the material.

Slip on Aids: Your therapist can tell you about other products that can make it easier to put on your compression garment.

Compression Garment Resources

Insurance Coverage for Compression Wraps: Your lymphedema therapist will give you a list of supplies before you start treatment. Many insurance companies do not cover compression wraps. Some companies will pay for wraps purchased from Sun Medical Company (www.sunmedical.com or 1-800-714-7434). If your insurance company denies your claim, provide a copy of the NC Mandate along with a note explaining the wraps are for treatment of lymphedema. The NC Mandate is available at www.ncleg.net/sessions/2009/bills/house/PDF/H535v4.pdf. If you do not have internet at home, ask your therapist for a copy.

Sample locations where to buy compression wraps:

Academy of Lymphatic Studies
11632 High Street Suite A
Sebastian, Florida 32958
1-800-863-5935
www.ACOLS.com

Advanced Homecare
105 W. Hwy. 54, Suite 267
Durham, NC 27713
Phone: 919-544-0120
Fax: 919-806-3397

Alexander Health Services
500 East Wait Avenue, Suite 1
Wake Forest, NC 27587
Phone: 919-556-8934
Fax: 919-633-3117

Your lymphedema therapist will give you a list of the local providers and the supplies you need to purchase.

Caring for Scars

You may have a scar or scars from surgery or radiation therapy. Scars usually heal about 6 weeks after surgery. Sometimes scars may be red and tight and feel like they are pulling your skin. Do not massage any scar until you have talked with your lymphedema therapist.

Surgical Scars

You can gently massage the scar tissue in a circular motion for 5 minutes each day. Use a firm motion but not enough pressure to cause a burning sensation or uncomfortable pulling on the area. You can spend extra time on any area that feels “stuck”. Do not use lotion while you are doing this. After you are done each day, apply Vitamin E oil to the scar.

You can stretch the skin next to the scar. Put 2 or 3 fingers at the top of the scar and stretch the skin above the scar in parallel direction. Then move your fingers a bit lower and repeat the stretch. Do this all the way down the length of the scar.

Radiation Scarring

Scarring from radiation treatments can continue for up to 6 months after your radiation therapy ends. Do not begin any massage until at least 6 weeks after your therapy is over and you have no scabs or broken skin. Be very careful with your skin because it will be delicate and can break easily. Start with short massage sessions at first. You can slowly increase the amount of time as your skin heals. Move your fingers in a circular motion to gently stretch the skin. After your massage, apply lotion or Vitamin E cream to the scar. Talk with your therapist about products to help with scar healing.

Exercises to help with lymphedema

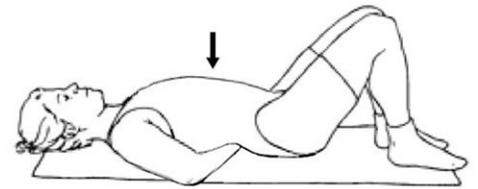
Certain exercises can help you drain extra fluid, especially in the first phases of treatment. Do these exercises in the order listed. Do each exercise 5 times. Talk with your therapist if you have problems with any of the exercises.

Stomach Breathing:

Lie on your bed or the floor or sit in a comfortable chair. Keep your knees slightly bent and your feet on the floor. Rest your hands on your stomach. Take deep breaths. As you take each breath, feel your stomach rise as you breathe in. Slowly breathe out through your mouth.

Pelvic Tilt:

Lie on your back with your knees bent and slightly apart. Keep your feet flat on the floor. Use your stomach muscles to tilt your pelvis and flatten your lower back to the floor. Hold this for a count of 5. Release and then repeat.



Pelvic Tilt

Neck Turns:

Breathe in and turn your head slowly to one side. Hold this for a count of 5. Exhale and return your head to the center. Repeat on the other side.

Head Tilt:

Gently bring your right ear toward your right shoulder. Hold this for count of 5. Bring your head back up to center. Repeat the same steps on the left side.

Shoulder Shrug:

Breathe in and lift both shoulders up towards your ears.

Breathe out and return to a relaxed position.



Shoulder Shrug

Shoulder Rolls:

Roll your shoulders back in a circular motion.



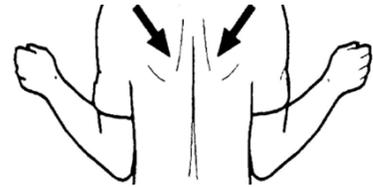
Shoulder Rolls

Exercises for arm lymphedema

The following exercises should also be done if you are at risk for arm lymphedema. Do each one 5 times.

Shoulder Blade Squeeze:

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



Shoulder Blade Squeeze

Hand Press:

Breathe in while pressing the palms of your hands together. Hold for a count of 5. Relax and breathe out.

Hand Press



Elbow Bend:

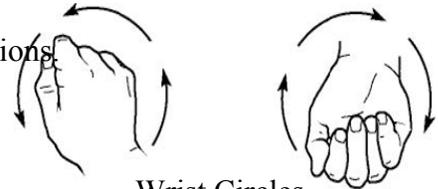
Bring your hand towards your shoulder. Return your hand beside your body.



Elbow Bend

Wrist circles:

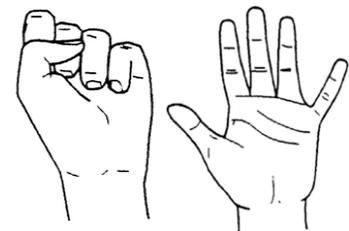
With your hand in a fist, make small circles with your wrist in both directions.



Wrist Circles

Fist Clench:

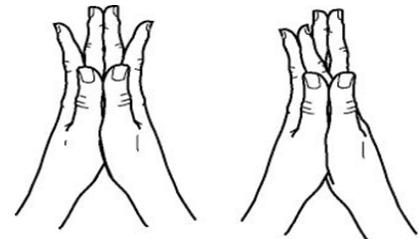
Make a fist. Hold for a count of 5. Slowly open your hand and straighten your fingers.



Fist Clench

Finger Stretch:

Place your palms together. Move your fingers away from each other, one pair at a time. Next, move your fingers from one side to the other with them together.



Finger Stretch

Do 5 more stomach breathing exercises. Then lie down and raise your arm on a pillow for a few minutes.

Exercises for leg lymphedema

The following exercises should also be done if you are at risk for leg lymphedema. Do each one 5 times.

Knee Bends:

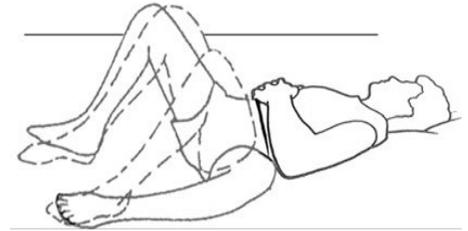
Lie on your back with both legs straight. Slide one leg up, bending your knee. Then slide it back down. Repeat with the other leg.



Knee Bends

Leg Drops:

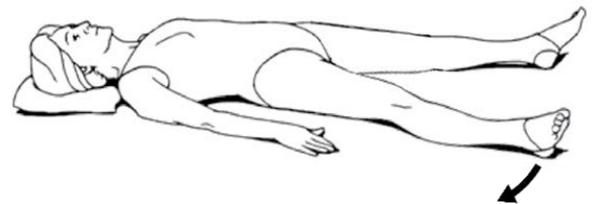
Lie on your back with both knees bent. Keep your feet flat on the floor. With one leg in place, slowly lower the other leg out to the side. Bring it back to center. Repeat with the other leg.



Leg Drops

Leg Slides:

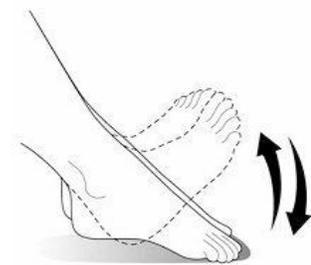
Lie on your back with your legs straight. Slide your leg out to the side and then return it to the center. Keep your knees straight and your kneecap facing up. Repeat with the other leg.



Leg Slides

Ankle Pumps:

Move your foot up and down as if you are pushing a gas pedal in a car. Repeat with the other foot.



Ankle Pumps

Ankle Writing:

Pretend to write on the floor as if your big toe was a pen.

After you have done all of the exercise, do 5 more stomach breathing exercises. Then lie down and raise your leg on a pillow for a few minutes.

More Exercise

Get Moving

The lymphedema exercises on the earlier pages are important. And so is general exercise in keeping yourself fit. 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 . Once you are comfortable at this level, try adding more moderate activities, such as hiking, 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. See the walking program below 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.

	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.			

What if I have more swelling than I've been having?

You can keep track of your swelling by measuring the area and comparing side to side. (See the next page) Use the sheets on the next pages to track your measurements. If you notice an increase in swelling, consider the following tips:

- Wear your garments correctly.
- Your garments need to be replaced your garments every 3 to 6 months.
- Make sure you have not had an injury to the affected area, a bug bite or a scratch or scrape.
- Exercise, drink plenty of fluids, and a eat a healthy diet each day.
- Increase your self manual lymphatic drainage to 3 to 4 times a day.
- Wrap the area for 3 to 5 days in a row (24 hours a day).
- Keep cool. Do not allow yourself to get overheated.
- Elevate the affected area whenever possible.

Call your care team if you have any of the following:

- | | |
|--|--|
| ① Fever of 100.5° F or higher | ① Increase in swelling |
| ① Rash on your skin in the affected area | ① New or unusual pain |
| ① Redness or warmth in the area | ① Shortness of breath, trouble breathing |

If you have any of these signs of infection, you need to contact your care team or your primary care provider at once. Take off your compression garment and do NOT do any massage or drainage to the area. After you have been seen and treated, your therapist will tell when you can restart your lymphedema therapy.

Want to learn more?

National Lymphedema Network (NLN)
<http://www.lymphnet.org/>

Lymphatic Research Foundation
www.lymphaticresearch.org

Lymph Notes
www.lymphnotes.com

Lymphedema People
www.lymphedemapeople.com

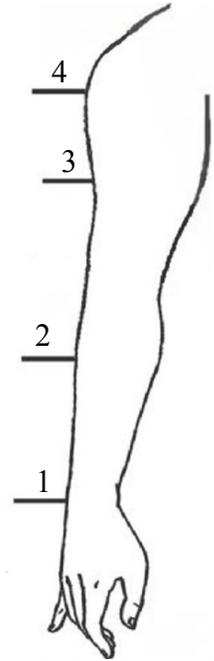
Circle of Hope Lymphedema foundation
www.lymphedemacircleofhope.org

Lighthouse Lymphedema Network:
www.lymphedemalighthouse.org

Also, see the following pages for more resources

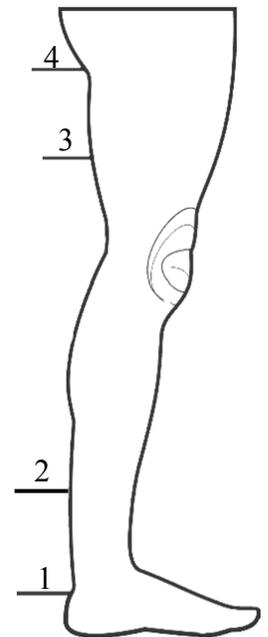
Measuring Yourself at Home

Arm Measuring: Make a mark at your wrist (1), forearm (2), upper arm (3) and armpit (4). Measure, in centimeters, from the nail bed of your middle finger to each of the marks, 1 to 4. Write down these measurement in the first column of the table below. These will help you to measure at the same place each time you measure. At each mark, measure the circumference (distance around) the arm. Write each measurement down in the correct box. Do this on the right and left sides and compare sides.



Area Measured	Date															
	R	L	R	L	R	L	R	L	R	L	R	L	R	L	R	L
1- Wrist _____ cm																
2- Forearm _____ cm																
3- upper arm _____ cm																
4- Armpit _____ cm																

Leg Measuring: Make a mark at your ankle (1), mid lower leg (2), mid upper leg (3) and near the groin (4). Measure, in centimeters, from the bottom of your heel to each of the marks, 1 to 4. Write down these measurement in the first column of the table below. These will help you to measure at the same place each time you measure. At each mark, measure the circumference (distance around) the leg. Write each measurement down in the correct box. Do this on the right and left sides and compare



Area Measured	Date															
	R	L	R	L	R	L	R	L	R	L	R	L	R	L	R	L
1- Ankle _____ cm																
2- Mid lower leg _____ cm																
3- Mid upper leg _____ cm																
4- Groin _____ cm																

If you notice a difference of 2 centimeters or more, call your lymphedema therapist and follow the guidelines on page 10.

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>

Comprehensive Cancer Support Program

Lymphedema Services

Carolina Pointe II

6011 Fearington Rd, Ste 304

Chapel Hill, NC 27517

CPII clinic 919-957-6600

Counseling 919-966-3494

CPII clinic 919-957-6600

Counseling 919-966-3494

Link to find lymphedema therapists: <http://unclineberger.org/ccsp/programs>

unclineberger.org/ccsp/programs

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/>

Lymphedema Resources

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.

Lymphedema Resources

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
 - Charity Care: 919-966-3425
- **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>
- **1 in 9:** The mission of 1 in 9 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. 1 in 9, 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/>
- **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>. <http://lymphedematreatmentact.org/>
- **National Lymphedema Network Marilyn Westbrook Garment Fund:** pays for one set of garments per applicant per calendar year; must be NLN member receiving treatment at a clinic or with a therapist affiliated with NLN; must show demonstrated financial need. Call 800-541-3259 or go to <http://lymphnet.org/patients/garment-fund>
- **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>

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/>

Lymphedema Resources

- **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>

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 Workbook Evaluation

Please complete the evaluation at www.carolinawell.org (look under announcements for link) or mail this evaluation to M.Gellin, UNC Lineberger Comprehensive Cancer Center, 1700 Martin Luther King Blvd, Campus Box 7294, Chapel Hill, NC 27599. Please take a few minutes to complete this brief survey. We are always looking at ways to improve our educational materials. You may choose not to answer any of the questions. When appropriate please circle your choices. Thank you!!

DATE _____

1. Age: _____
2. What county of NC do you live in?

3. Race/Ethnicity (please check all that apply):

<input type="checkbox"/> American Indian and Alaska Native	<input type="checkbox"/> Hispanic or Latino
<input type="checkbox"/> Asian	<input type="checkbox"/> Native Hawaiian/Other Pacific Islander
<input type="checkbox"/> Black or African American	<input type="checkbox"/> White
4. Do you have (or have you had) a cancer diagnosis? Yes No
5. If yes to question #4, what type of cancer?

<input type="checkbox"/> Breast	<input type="checkbox"/> Prostate	<input type="checkbox"/> Other:
<input type="checkbox"/> Colon	<input type="checkbox"/> Lung	
6. Are you a:
 - Person with lymphedema
 - Friend /loved one of someone with lymphedema
 - Lymphedema provider
 - Health care provider
7. Overall, how would you rate this workbook?
 - Poor Fair Good Excellent
8. Was the workbook too long?
 - Yes No
9. Was the workbook easy to understand?
 - Yes No

10. As a result of reading this workbook I feel I have a better understanding of:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
a) what lymphedema is	<input type="checkbox"/>				
b) what the signs and symptoms of lymphedema are	<input type="checkbox"/>				
c) what I should do first if I notice swelling changes	<input type="checkbox"/>				
d) the importance of having treatment with a certified lymphedema therapist	<input type="checkbox"/>				
e) how I can lower my risk of lymphedema	<input type="checkbox"/>				
f) what treatment is used for lymphedema	<input type="checkbox"/>				
g) how I can reduce lymphedema symptoms if I have lymphedema	<input type="checkbox"/>				
h) self-care for lymphedema after completing treatment with a lymphedema therapist	<input type="checkbox"/>				
i) how to find local resources for lymphedema	<input type="checkbox"/>				

Thank you for your participation and feedback! Please give us your suggestions to improve the workbook (use back of form as needed).



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