Lymphedema Therapy

Treatment Care Packet

Hartford HealthCare
Rehabilitation Network

860.696.2550
HHCRehabNetwork.org

Hartford HealthCare
Rehabilitation Network

Dear Client,

Welcome to our Hartford HealthCare Lymphedema Program! We are glad you are here, and we look forward to working with you to reduce and manage the edema you are experiencing. This booklet contains valuable details about our program, and educational information about lymphedema. This information can help prepare you for both the intensive phase and home management phase of your treatment.

The lymphedema program at HHCRN was awarded the designation of ***Center of Excellence*** by the Lymphatic Education and Research Network (LE&RN) for our comprehensive approach that is dedicated to the highest standard of care for patients with lymphedema. If you are just beginning your journey with lymphedema, or have been dedicated to your home program for many years, we are glad to partner with you. We are here to support you as you discover more about this disease, and provide the tools you need to manage it successfully. Please feel free to ask your therapist any questions you have as you go through this therapeutic process. We encourage you to keep this booklet to refer back to as your understanding of lymphedema develops.

Thank you again for choosing Hartford HealthCare for your lymphedema care.

Linda Hodgkins

Sincerely,
Linda Hodgkins MS OTR/L CLT-LANA
Lymphedema Clinical Program Manager
Linda.Hodgkins2@HHCHealth.org

Lymphedema Treatment – *What to expect during therapy*

To do before the first day:

Order your bandages needed for therapy as soon as possible to ensure they arrive before your first appointment *(see order form from your therapist for instructions)*. You will need these bandages for the first day of treatment. Please bring all of the ordered supplies with you.

What to Wear:

For arm treatment: loose fitting shirt *(preferably short sleeve)*.

For leg treatment: loose fitting pants/shorts/skirt, large shoe or cast shoe.

1st treatment will include:

Cutting foam to fit your arm or leg, bandaging your limb with layers of foam and bandages, and manual lymph drainage massage *(if time permits)*. You will be asked to remove clothing during the session so that the massage is directly on the skin. Sheets will be provided to ensure your privacy. You may be introduced to exercises to perform while bandaged.

The goal of therapy is to wear compression bandaging for 22-24 hours. You can remove your bandages to shower approximately 2 hours prior to your next appointment. Please **roll your bandages,** and bring all supplies with you to the next appointment.

If you experience prolonged pain, numbness, or tingling in the bandaged limb, follow the bandaging guidelines found in this booklet.

Course of treatment:

- In general you will be seen 5 days a week for 2 weeks, then 3 times a week for 1-2 weeks. This protocol may differ per therapist recommendation and your specific presentation of swelling.
- At the end of the first week, or the middle of the second week, your therapist will measure for compression garments.

- Garments should arrive in 1-2 weeks from order day.
- Once garments have arrived, your therapist will teach you how to put them on and take them off and care for them.

We recommend a follow up evaluation in 6 months or when directed by your therapist.

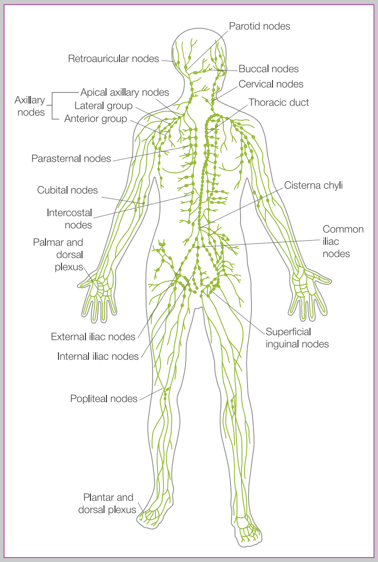
Please call or email your therapist with questions or concerns.

It is a privilege to partner with you and provide your lymphedema care.

INSURANCE COVERAGE INFORMATION

Insurance typically covers the expense of lymphedema therapy. However, Medicare and commercial insurance do not cover the cost of the bandages used during therapy. You will be given instructions on how to purchase these bandages by your therapist at the initial evaluation. The cost of the bandages is $50-90 per set per limb. These bandages last up to one year with proper care (see bandage care instructions in this booklet). The bandages are considered "supplies" and are not usually covered by insurance. The codes listed below are used to represent the bandages you will need. You can use these codes to check coverage with your insurance policy if you have additional questions.

At the conclusion of therapy, we will measure and fit you with appropriate compression garments to maintain the edema reduction achieved during the active phase of therapy. These garments are not covered by Medicare. Coverage for these compression garments varies from policy to policy for private insurance carriers. We have provided the codes for these garments below so that you can check your specific coverage. We work with several durable medical equipment vendors who will provide you with the garments. We will do the measurements and fitting for your garments, and the equipment vendor will check on your particular insurance coverage and bill your insurance company for the garments. If you have any questions about insurance coverage, please bring them to the attention of our therapist.



CODES FOR BANDAGES AND COMPRESSION GARMENTS

Bandages used during therapy:

A6441	cotton padding
A6442	6cm short stretch bandage
A6443	8, 10, or 12cm short stretch bandage
A6446	finger/toe bandage
A6457	tubular stockinette, with or without elastic
A6449	Lenkelast (used to attach the foam pieces)

Compression Garments worn after therapy is completed:

A6530	Compression stocking, below knee 20-30 mm hg
A6531	Compression stocking, below knee 30-40 mm hg
A6532	Compression stocking, below knee 40-50 mm hg
A6533	18-30 mm hg Thigh high Compression stocking
A6534	30-40 mm hg Thigh High Compression Stocking
A6535	40-50 mm hg Thigh High Compression Stocking
A6539	Compression Panty Hose 18-30 mm hg
A6540	Compression Panty Hose 30-40 mm hg
A6541	Compression Panty Hose 40-50 mm hg
A6542	Custom Compression Panty Hose
S8420	Custom Sleeve and glove- 1 piece
S8424	Compression Sleeve
S8428	Compression Gantlet
S8427	Compression glove with finger stubs
S8426	Custom glove heavy weight
L3999	Belisse Compression Bra uses a "miscellaneous" code
E1399	Solaris Tribute garment (worn at night to replace multi-layered bandaging)
S8422	Custom arm sleeve, medium weight
S8423	Custom arm sleeve, heavy weight

Care of Your Lymphedema Bandages

Lymphedema bandages will have a long life if cared for properly. Please follow the guidelines outlines below.

1. Wash your bandages at least once a week to restore their elastic properties. Wash more often if the bandages become soiled or stained. Wash the material that is against your skin (Stockinette) daily to remove skin oils and perspiration.

2. In lukewarm water, use a mild, liquid detergent such as Dreft (for infants) or the liquid detergents that indicate “Free and Clear” on the bottle. Do not use fabric softeners or Woolite. Avoid powdered detergents because the soap powder can cling to the bandages.

3. Do not wash the foam pieces or cotton padding.

4. Toe/Finger bandages do not have a long life– perhaps one or two wears. Do not launder these bandages.

5. Wash items by hand, or use a lingerie (mesh) bag or pillow case (with a zippered top) if using the washing machine.

6. Dry all bandages on a flat surface if possible. If hanging bandages, fold them in half so that they will not stretch. Do not wring or stretch the bandages while they are wet. Note: Stockinette can be machine washed and air dried.

7. Please roll the bandages after each use.

8. Please roll the bandages after they have dried following laundering.

Bandage Protocol

1. If bandages cause any pain, rubbing, throbbing, discoloration, numbness, or tingling, try changing the positions of your limb. If it does not improve, remove outer most bandage. If pain continues, remove all bandages from the limb in pain. Note the area(s) of discomfort and report all details to your therapist during your next treatment session.

2. If bandages remain comfortable, wear them until it is time to get ready for therapy the following day unless advised otherwise by your therapist. Remove bandages and shower or bathe limb with soap. Apply lotion such as Eucerin to limb. Then kindly roll all bandages and bring them to your next treatment session, along with foam, cotton, and remaining bandaging materials.

Nutrition Guidelines

Good nutrition is important for overall health, weight management, and the prevention of chronic diseases.

It is equally important for people who suffer from lymphedema, the primary symptoms of which include swelling, pain and tenderness – all of which can be reduced through proper nutrition and exercise.

Several recent research studies have demonstrated this relationship between nutrition and exercise and lymphedema symptoms. These include:

Eating Right: Where to Start

A healthy diet and weight for those with lymphedema begin with eating right. This includes consuming well-balanced meals consisting of lean meats, beans, lower-fat dairy, fruit, vegetables, and whole grains. Each of these is important in providing adequate nutrition and balance. It is also important to consume the right amount of calories and incorporating a variety of whole foods, rather than highly processed foods which tend to contain less healthy ingredients and higher calories. Portion control is also critical in achieving and maintaining a healthy weight. The average adult portion size found in most restaurants is 2-3 times the amount that it should be. If hunger is a problem, aim to consume frequent low-calorie, filling snacks, such as a few almonds or a piece of low-fat cheese, throughout the day and drink a tall glass of water before meals in order to fill up and avoid overeating.

Including Exercise

Physical activity strengthens the immune system, and enhances and supports digestive system activity. In addition, exercise has been shown to improve lymphedema symptoms. It is recommended to begin with 30 minutes of moderate activity each day. Sedentary people or those with limited mobility are encouraged to do so in small, manageable amounts. Even a brief slow walk can provide benefits. It is important to always consult with your physician before doing any new exercise routine or vigorous activity.

In summary, nutrition and exercise can help in managing lymphedema symptoms by following these simple strategies:

1. Consume healthy, well-balanced meals focused on a variety of fruits, vegetables, whole grains, beans, nuts, lean protein, and low-fat dairy foods.
2. Achieve and maintain a healthy weight.
3. Be mindful of total calorie intake.
4. Avoid high-calorie prepared and convenience foods and "empty calories."
5. Include regular physical activity as best able, with the permission of your physician.

Iannotta, J., MS, RD, CSO, CDN. (2012, December 1). General Nutrition Guidelines for the Patient with Lymphdema. Meals to Heal, 10(12), 34-37.

Reduce Risk for Infection

Skin Care - Avoid Trauma / Injury to Reduce Infection Risk

- Keep extremity clean and dry.
- Apply moisturizer daily to prevent chapping/ chafing of skin.
- Attention to nail care; do not cut cuticles.
- Protect exposed skin with sunscreen and insect repellent.
- Use care with razors to avoid nicks and skin irritation.
- If possible, avoid punctures such as injections and blood draws.
- Wear gloves while doing activities that may cause skin injury (e.g. washing dishes, gardening, working with tools, using chemicals such as detergent).
- If scratches/punctures to skin occur, wash with soap and water, apply antibiotics, and observe for signs of infection (i.e. redness).
- If a rash, itching, redness, pain, increased skin temperature, increased swelling, fever or flu-like symptoms occur, contact your physician immediately for early treatment of possible infection.

Avoid Limb Constriction

- If possible, avoid having blood pressure taken on the at-risk extremity, especially repetitive pumping.
- Wear non-constrictive jewelry and clothing.
- Avoid carrying a heavy bag or purse over the at-risk or lymphedematous extremity.

Compression Garments

- Should be well-fitting.
- Support the at-risk limb with a compression garment for strenuous activity (i.e., weight-lifting, prolonged standing, and running) except in patients with open wounds or with poor circulation in the at-risk limb.
- Patients with lymphedema should consider wearing a well-fitting compression garment for air travel.

NLN Medical Advisory Corporation. (2012, May 1). Position Statement of the National Lymphedema Network. Summary of Lymphedema Risk Reduction Practices, 1-2.

Reduce Risk for Infection

Activity / Lifestyle

- Gradually build up the duration and intensity of any activity or exercise. Review the Exercise Position Paper.

  https://www.strengthandcourage.net/lymphedema/
- Take frequent rest periods during activity to allow for limb recovery.
- Monitor the extremity during and after activity for any change in size, shape, tissue, texture, soreness, heaviness or firmness.
- Maintain optimal weight. Obesity is known to be a major lymphedema risk factor.

Extremes of Temperature

- Use common sense and proceed cautiously when using heat therapy. Observe if there is swelling in the at-risk limb or increased swelling in the lymphedematous limb and cease use of heat such as a hot tub or sauna.
- Avoid exposure to extreme cold, which can be associated with rebound swelling, or chapping of skin.
- Avoid prolonged (greater than 15 minutes) exposure to heat, particularly hot tubs and saunas.

Additional Practices Specific to Lower Extremity Lymphedema

- Avoid prolonged standing, sitting or crossing legs to reduce stagnation of fluid in the dependent extremity.
- Wear proper, well-fitting footwear and hosiery.
- Support the at-risk limb with a compression garment for strenuous activity except in patients with open wounds or with poor circulation in the at-risk limb.

Air Travel

Air travel presents several considerations for individuals with lymphedema and for those at risk for lymphedema. It is the position of the National Lymphedema Network that:

- Individuals with a confirmed diagnosis of lymphedema should wear some form of compression therapy while traveling by air.
- Individuals at risk for developing lymphedema should understand the risk factors associated with air travel and should make a decision to wear compression based on their individual risk factors.

During air travel, certain individuals may require the added compression afforded by bandaging. These persons should:

- Be trained by a lymphedema specialist in appropriate bandaging techniques.
- Apply the compression bandages before flying.
- Leave the bandages on until you reach your final destination.
- While away from home, continue your regular schedule of garment and bandage wear.
- Avoid carrying heavy bags or using shoulder straps on the affected arm.
- Use roller bags or obtain assistance for carrying, lifting and transporting luggage.
- Wear loose fitting, non-constricting clothing.
- Move about the cabin frequently if possible to enhance contribution of the "muscle pump."
- Throughout your trip, try to avoid excessive activities of the type that tend to exacerbate your swelling, take frequent breaks for rest and elevation, and get adequate sleep.
- Ensure adequate fluid intake during flight and throughout your trip.
- Maintain healthy eating habits, minimizing alcohol, caffeine and salty foods.
- Consider bringing antibiotics with you, especially when travelling outside the U.S. or if you have a history of cellulitis in the affected limb.
- Wear a LYMPHEDEMA ALERT Bracelet and/or necklace.

NLN Medical Advisory Corporation. (2012, July 1). Position Statement on Air Travel from the National Lymphedema Network. Summary of Lymphedema Air Travel Practices, 3-4.

Lymphedema Resource Guide

Non-Profit Organizations

www.lymphaticnetwork.org Lymphatic Education & Research Network (LE&RN); phone: 516-625-9675

www.lymphnet.org National Lymphedema Network (NLN); phone: 646-722-7410

Additional Online Resources

www.alfp.org American Lymphedema Framework Project

www.breastcancer.org/treatment/lymphedema/treatments/pumps

www.cancer.org American Cancer Society > Treatment & Support > Managing Side Effects

www.cancer.gov/about-cancer/treatment/side-effects/lymphedema/lymphedema-pdq National Cancer Institute

www.lymphcareusa.com Online resource for patients, families, and caregivers

www.lymphaticnetwork.org/symposium-series LE&RN video library offering presentations from world-renowned doctors, lymphedema therapists and others specializing in lymphatic disease.

www.lymphaticnetwork.org/expo LE&RN's Virtual Expo is a resource for those seeking treatment options. Information on garments, pneumatic pumps and other products can be viewed directly from each company through educational videos, downloads and links.

www.lymphaticnetwork.org/living-with-lymphedema/lymphedema Lymphedema FAQs

www.youtube.com/watch?v=o_lnoL4ssFk LE&RN Symposium (Living with Lymphedema: One Nurse's Journey as Patient and Advocate; Catherine Holley RN, Massachusetts General Hospital, Boston, MA)

www.livestrong.org/we-can/finishingtreatment/lymphedema LIVESTRONG

www.lbbc.org Living Beyond Breast Cancer

www.lymphnotes.com/ Online resource for those living, with or at risk of developing lymphedema. Also for the family, friends and therapists who care for these individuals.

www.lighthouselymphedema.org The Lighthouse Lymphedema Network is an organization of individuals who are lymphedema patients, or have an interest in lymphedema.

www.lymphedematreatmentact.org Information on the federal bill to improve insurance coverage.

Internet Blogs

www.lymphedemablog.com/ By Joe Zuther, Lymphedema Specialist (aka Lymphedema Guru)

www.lymphedemapeople.com/ A site for people with lymphedema, made by people with lymphedema

www.thelymphielife.com By Alexa Ercolano, a primary LE patient

http://staylymphiestrong.com/ By Vern Seneriz, a primary LE patient

http://stepup-speakout.org/ SU-SO—Together We Can Make the Difference in Lymphedema

Locate a Certified Lymphedema Therapist/Lymphedema Center

www.lymphaticnetwork.org Membership & Chapters > US State Chapter > State > Lymphedema Center. There is a growing list of states. Enter Zip Code to locate lymphedema center with CLT on staff.

www.klosetraining.com > therapist-directory

www.clt-lana.org > search > therapists

www.nortonschool.com/therapistreferrals_form.html

www.acols.com/find-therapist/

Look4LE Smart Phone App

Massachusetts Lymphedema Supportive Network

https://lymphaticnetwork.org/chapters/massachusetts The Massachusetts Chapter of the Lymphatic Education & Research Network (LE&RN) is a supportive network for patients, caregivers, lymphedema clinicians and others throughout Massachusetts and the surrounding region.

On Facebook: Lymphatic Education & Research Network, Massachusetts Chapter

Social Media Support Groups/Networks

Official Lymphie Strong Inspiration Group (Facebook)

The Lymphedema Running & Fitness Club (Facebook)

Lymphedema (Facebook)

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Lymphatic Education & Research Network
Connecticut Chapter

lymphticnetwork.org/chapters/connecticut

Lymphatic Education
& Research Network

Centers of Excellence

Welcome TO A LYMPHATIC EDUCATION & RESEARCH NETWORK (LE&RN) CENTER OF EXCELLENCE IN THE DIAGNOSIS AND TREATMENT OF LYMPHATIC DISEASES

What It Means to Be a Center of Excellence

Where you see a **LE&RN Centers of Excellence** logo, you know you're visiting an institution that sets the highest standard for best practice multidisciplinary care in the management and care of lymphatic diseases (LD) such as lymphedema (LE), lipedema (LI), and lymphatic malformation (LM).

All institutions designated as a **Center of Excellence** have been evaluated by international leaders in an extensive review process.

Center of Excellence Designations

Each **Center of Excellence** has been awarded a designation corresponding to the level of care provided. To see the full list of services provided by each Center designation, visit the Centers of Excellence link found on the LE&RN website homepage: **https://lymphaticnetwork.org/centers-of-excellence. There are five designations:**

Comprehensive Center of Excellence (COE) designation indicates that an institution can provide the listed services on-site, all within the same institution, and can coordinate provision of the services.

Network of Excellence designation indicates that an institution and its affiliate institutions (within walking distance) can provide the listed services.

Referral Network of Excellence designation indicates that the institution and/or nearby collaborating institutions can provide the listed services, and that these institutions can coordinate provision of the services.

Lymphatic Disease (LD) Surgery COE designation indicates that an institution (usually, a cancer care center) can provide the listed surgical services.

LD Conservative Care COE designation indicates that an institution can provide the listed conservative care services.

We Need Your Support to Make the Centers Successful!

Each Center shares LE&RN's commitment to quality care and is dedicated to a team approach of working with LE&RN and Patient Affiliate Boards to continually monitor and improve care. You can help by completing the Patient Survey at **www.COESurvey.org**. Email LE&RN at **COE@LymphaticNetwork.org** with any questions.

Join LE&RN's International Patient Registry

This registry is a confidential database that is a crucial resource for researchers seeking treatments and cures for lymphatic diseases. Please join at the link provided: **https://lernregistry.stanford.edu/**

Additional Resources for the LD/LE Community

At LE&RN, our goal is to bring you resources that help improve the quality of life for people who have lymphatic diseases (LD). Go to **LymphaticNetwork.org** for ways to get educated and connected to the community:

- Access to an extensive printable library of ***Resource Downloads***
- LE&RN ***Educational Videos*** filled with presentations from world experts
- ***Ask the Experts,*** an online forum where you ask experts your question
- A ***Virtual Expo*** where you can learn about LE/LD care products
- Sign up for ***E-Newsletters*** to stay informed and connected to the community
- Read ***Your Stories,*** written by those with LD from around the world
- Celebrate ***World Lymphedema Day,*** March 6
- Join or start a LE&RN ***Chapter*** in your region, state, or country

Become a Supporting Member of LE&RN

LE&RN is *your* organization and survives because of *your* investment. Please become a LE&RN Supporting Member today so that we can all continue our strides forward for the lymphatic community: **https://lymphaticnetwork.org/supporting-member**

Lymphatic Education
& Research Network

261 Madison Avenue, 9th Floor
New York, NY 10016 • 516-625-9675

lern@LymphaticNetwork.org
www.LymphaticNetwork.org

Hartford
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Rehabilitation Network