Lymphedema Therapy
Treatment Care Packet
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.

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

**Treatment:**
Insurance typically covers all or most of the expense of treatment for lymphedema. Please refer to the benefit sheet that was provided to you when you filled out paperwork for your evaluation. For further clarification of your benefits, please either contact your insurance company or request an estimate from the front desk. You can use the common treatment codes that are listed below to check coverage with your insurance carrier.

<table>
<thead>
<tr>
<th>Evaluation</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>97110</td>
<td>Therapeutic Exercise</td>
</tr>
<tr>
<td>97140</td>
<td>Manual Therapy</td>
</tr>
<tr>
<td>97530</td>
<td>Therapeutic Activity</td>
</tr>
<tr>
<td>97535</td>
<td>Self-care/home management training</td>
</tr>
</tbody>
</table>

**Bandaging supplies:**
Most insurance plans do not cover the cost of the supplies that are necessary for treatment. If you have additional questions about your coverage for bandaging supplies, you can use the codes that are listed below to check coverage with your insurance carrier. The list below is not exhaustive of all codes – ask your therapist for guidance if needed.

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
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<tbody>
<tr>
<td>A6599</td>
<td>Short stretch bandage any width</td>
</tr>
<tr>
<td>A6596</td>
<td>Conforming gauze any width</td>
</tr>
<tr>
<td>A6594</td>
<td>Bandage liner lower extremity any size</td>
</tr>
</tbody>
</table>

The cost of bandages varies based on your presentation, but can be anywhere from $50 to $125 per limb. These bandages can last for several years with proper care (see bandage care instructions in this booklet). During your initial evaluation, you will be given instructions on how to purchase the specific supplies you will need. Your therapist will guide you in replacing items as needed during future episodes of care.

**Garments:**
At the conclusion of treatment, your therapist will measure you for and fit you with appropriate compression garments that will help you maintain the achieved reduction in your swelling.

Insurance coverage of these garments varies from policy to policy. In order for insurance to cover the cost of garments, they must be billed by a durable medical equipment (DME) vendor. Hartford Healthcare is not a DME vendor, so it is necessary for your therapist to work with a third party DME to investigate your coverage. Your therapist may relay your garment coverage information and/or you may be contacted directly by the DME vendor. Your therapist can provide you with contact information for the DME vendor for any questions you may have related to your insurance coverage for garments. You may also use the codes that are listed below to check coverage directly with your insurance carrier. The list below is not exhaustive of all available codes – ask your therapist for guidance if needed.

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
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<tbody>
<tr>
<td>A6530</td>
<td>Compression stocking below knee 18-30mmHg</td>
</tr>
<tr>
<td>A6552</td>
<td>Compression stocking below knee 30-40mmHg</td>
</tr>
<tr>
<td>A6610</td>
<td>Custom compression below knee 18-30mmHg</td>
</tr>
<tr>
<td>A6556</td>
<td>Compression stocking thigh length 18-30mmHg</td>
</tr>
<tr>
<td>A6557</td>
<td>Compression stocking thigh length 30-40mmHg</td>
</tr>
<tr>
<td>A6558</td>
<td>Compression stocking thigh length 40mmHg or &gt;</td>
</tr>
<tr>
<td>A6556</td>
<td>Custom compression thigh length 18-30mmHg</td>
</tr>
<tr>
<td>A6539</td>
<td>Compression stocking waist length 18-30mmHg</td>
</tr>
<tr>
<td>A6540</td>
<td>Compression stocking waist length 30-40mmHg</td>
</tr>
<tr>
<td>A6584</td>
<td>Compression wrap with adjustable straps NOS</td>
</tr>
<tr>
<td>A6527</td>
<td>Custom compression full leg/foot, padded for night</td>
</tr>
<tr>
<td>A6530</td>
<td>Custom compression stocking to waist 18-30mmHg</td>
</tr>
<tr>
<td>A6547</td>
<td>Custom compression arm sleeve &amp; glove combination</td>
</tr>
<tr>
<td>A6578</td>
<td>Compression arm sleeve</td>
</tr>
<tr>
<td>A6582</td>
<td>Compression gauntlet</td>
</tr>
<tr>
<td>A6581</td>
<td>Compression glove</td>
</tr>
<tr>
<td>A6580</td>
<td>Custom compression glove heavy weight</td>
</tr>
<tr>
<td>A6528</td>
<td>Compression garment, bra for nighttime use</td>
</tr>
<tr>
<td>A6589</td>
<td>Compression wrap with adjustable straps, bra</td>
</tr>
<tr>
<td>A6576</td>
<td>Custom compression arm sleeve, medium weight</td>
</tr>
<tr>
<td>A6577</td>
<td>Custom compression arm sleeve, heavy weight</td>
</tr>
<tr>
<td>A6523</td>
<td>Custom compression for arm, padded for night</td>
</tr>
</tbody>
</table>
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.
Garment Fitting and Education

As part of your treatment plan, your lymphedema therapist will measure and fit you with compression garments as indicated. These are general guidelines to follow:

• Wash your compression garments daily after each use. Natural body oil and skin flakes can prematurely age the elastic in your garment if they are not removed regularly through daily washing. Washing daily helps prolong the life of your garment.

• Daily washing of your garment resets the compression strength and fit. The garment stretches out with wear, and needs to be washed daily to reset the original size and shape of the garment. Swelling can increase if the garment is not washed daily.

• It is recommended to use a mild detergent that has the words “Free and Clear” that has no dye or perfume, and wash garments in warm or cold water. Machine washing is preferred to get the garment as clean as possible. A mesh delicate garment bag is recommended for machine wash.

• Do not use any chlorine bleach, fabric softeners, powdered detergent, or other additives as these may damage the garment. Lay flat to dry.

• Use textured donning gloves to don your compression garments. Gently donning your garment with donning gloves can extends the life of your garment, and makes it easier to get the garment(s) on. It can also prevent the garment from getting holes, runs or snags. Pulling excessively on the top of a compression garment to don or doff can overstretch the fabric, and ruin the fit of the garment. (Example A)

• Garments should be well fitting and should not cause painful indentations or any skin irritations such as rashes or blisters.
Nutrition Guidelines

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.

Risk Reduction Practices

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.

Risk Reduction Practices

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.

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/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 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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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.
Lymphatic diseases take a variety of forms, but, in general, they have the capacity to affect virtually every organ in the body. These lymphatic diseases include, but are not limited to, primary and secondary lymphedemas, lymphangiomas, cystic hygromas, lymphangiectasias, lymphangiomatosis, and syndromes of mixed lymphatic and vascular anomalies, along with a variety of other developmental disorders that influence lymphatic competence.

The International Lymphatic Disease Patient Registry and Biorepository includes a representative and well-characterized population of patients, with associated biological materials (blood and tissue samples), to serve as a source for the clinical and laboratory study of lymphatic diseases. This registry is a confidential database that contains information about individuals who carry the diagnosis of a lymphatic disease, including lymphedema and lipedema. This comprehensive registry serves as a repository of information that will enhance the future ability of health care professionals to accurately identify, categorize, treat, and prevent these diseases. The Biorepository facilitates the availability of blood samples to lymphatic investigators for prospective research, including genetic and proteomic studies.

We invite you to participate in this highly significant development for the patient community. An international patient registry paves the way for future clinical trials of experimental drugs and therapies designed to treat lymphatic disease. We encourage all patients to participate in this important initiative.

To register please go to: https://LernRegistry.stanford.edu/

Patient information is the key to finding a solution as well as a critical resource to advance science and, ultimately, medical care.

For information about a Participant’s rights, questions, contact 1-866-680-2906.