



Department of Rehabilitation Services

Standard of Care: Lymphedema

Case Type / Diagnosis:

Lymphedema is an excessive accumulation of high protein fluid (lymph) in the interstitial spaces due to a disruption in the normal lymphatic transport. Over time, it can lead to fibrosis or hardening of the dermal tissue, chronic inflammatory reactions and poor healing. The most common type of lymphedema seen in the United States is secondary, or acquired, lymphedema, which is caused as a result of tumor, trauma, chronic venous insufficiency and treatment for medical conditions, most notably for breast cancer and other malignancies. Lymphedema may develop in an extremity, the breast, and/or in the face, neck or trunk as a result of damage to the lymphatic transport system in an adjacent part of the body. The majority of patients seen here, at Brigham and Women's Hospital, develop lymphedema as a result of breast cancer treatment; and therefore, the majority of research discussed in this standard of care will emphasize this patient population. All patients with lymphedema, or those at risk for its development, can be evaluated and treated in a manner consistent with this standard.

The incidence and prevalence of lymphedema in breast cancer survivors is variable, and some researchers have been able to establish risk factors for the development of lymphedema. In a study by Petrek et al in 1998, it was found that six to thirty percent of breast cancer survivors will develop lymphedema.¹ Its onset usually occurs up to three years following surgery, and there is a 49% chance of latent symptom expression (greater than 3 years following surgery) according to another study by the same author in 2001.²

In a study in 2004 by Armer and colleagues, the percentage of patients who developed lymphedema after cancer treatment ranged from 22-43%, and the number of lymph nodes removed correlated with the risk of developing lymphedema.³

In 2004, Ozaslan and Kuru, investigated risk factors associated with the development of UE lymphedema after an axillary node dissection in 240 subjects. They found that 28% of subjects developed lymphedema and its incidence was associated with axillary radiation therapy and an increased body mass index. The effect of age, diabetes, smoking, hypertension, chemotherapy, tamoxifen use, stage of disease and number of metastatic lymph nodes was not significantly related to an increased incidence of lymphedema.⁴

Possible ICD.9 codes: 457.0 post mastectomy lymphedema
 457.1 other lymphedema
 757.0 congenital, hereditary lymphedema
 709.2 scar condition and fibrosis of skin

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Indications for Treatment:

1. Loss of functional use of an upper or lower extremity (UE or LE) due to size, weight, and loss of motion
2. Girth measurements indicating > 2cm difference between the affected and non-affected limb at 3 measured points along the extremity
3. Scar tissue formation that limits normal range of motion (ROM) and function, and disrupts normal lymphatic drainage
4. Palliative care pain relief, comfort and prevention of further functional loss of the affected limb
5. Loss of range of motion that limits a patient's ability to obtain the proper radiation position

Contraindications / Precautions for Treatment:

General Contraindications

- No heat in the involved quadrant
- No blood pressure taken in the involved extremity
- No exercise with active infection
- No exercise with excessive pain
- No ultrasound in the involved quadrant for patients with a history of cancer only

General Precautions

- Rapid exacerbation of lymphedema as it may be a sign of a deep vein thrombosis or new malignancy
- New redness in the involved extremity as it may be a sign of infection
- Unmanaged lymphedema

Manual lymph drainage (MLD)

Contraindications:

1. Active infection: e.g. cellulitis
2. Signs and symptoms include: erythema, warmth, local edema, tenderness to touch, and potentially systemic signs of fever, chills and myalgias
3. Impaired arterial perfusion
4. Potential or known malignant tumor that has not been treated
5. Malignant tumor that is in the early stage of treatment and is in the area to be addressed with MLD. The patient should complete 2-3 cycles of chemotherapy prior to initiating treatment. See below for precautions in cases of palliative care.

Precautions:

1. History of cardiac disease, specifically congestive heart failure (CHF), obtain clearance from cardiologist to begin MLD
2. Renal failure
3. Current medical treatment for malignant tumor. MLD is considered palliative in this case and the patient, therapist and MD agree that the potential benefits of MLD in providing comfort outweigh the potential risk of spreading the disease.

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4. History of deep vein thrombosis and current use of anticoagulation medications.
5. History of insulin dependent diabetes mellitus (IDDM) or non-insulin dependent diabetes mellitus (NIDDM) as altering fluid balance may alter blood sugar levels

Compression Bandages and Garments

Contraindications:

1. Arterial disease and/or ulcers. An arterial Doppler or perfusion test can be used to rule them out.
 - a. Signs and symptoms of arterial disease include: diminished pulse compared to opposite extremity; pale, bluish, smooth, shiny and cold or clammy skin; and presence of arterial ulcers. Test for capillary refill in the nail beds.
 - b. Signs and symptoms of arterial ulcers: distal 1/3 of lower leg, small, round, shallow, little drainage, pain with elevation.
2. Signs of infection or wound

Compression Pumps

Contraindications:

1. Do not use on a brawny extremity, as it will be extremely painful. Soften tissues prior to using a compression pump.

Evaluation:

Medical History:

- Past medical history through patient interview, review of the medical record, computerized longitudinal medical record (LMR) and medical history questionnaire
- Previous and current oncological history including diagnosis; grade and stage of tumor; past, current and planned treatments; results of treatment and complications, if applicable

History of Present Illness:

- Past and current history of lymphedema, treatment and results. Current compliance with home exercise program and maintenance techniques
- Include history of complications that arose during the patient's course of treatment
- Review pertinent radiological studies and operative reports

Social History:

- Note the patient's prior functional level, family/caregiver support available, professional roles and expectations, social/family roles and expectations, leisure time activities and current level of function including ADL'S, work responsibilities, leisure tasks, and family roles
- Consider functional tasks that require upper extremity weight-bearing, excessive reaching, lifting or carrying loads with upper extremities.

Medications:

- Review the patient's current medications and consider the effects that an altered fluid balance will have on effectiveness or potency of these medications.

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- Educate patients regarding the need for increased blood sugar monitoring as treatment for lymphedema alters the fluid balance and may alter blood sugar levels.
- Common medications include analgesics, possibly narcotics for pain relief (percocet, oxycodone, oxycotin), chemotherapy agents (cytoxan, adriamycin, arimidex), hormone treatments, (tamoxifen, taxol), and/or neuromuscular medications (neurotin).
- Side effects of these medications are vast and may include:⁵
 1. Chemotherapy agents: nausea/vomiting, alopecia, increased risk for infection, cardiac toxicity, neuropathy, movement disorders, weakness, and memory deficits.
 2. Hormone therapy: hot flashes, peripheral edema, skin rash, nausea, arthralgias, myalgias, headaches, peripheral neuropathy, depression, dyspnea, thrombophlebitis
 3. Narcotic analgesics: lightheadedness, dizziness, sedation, dysphoric mood
 4. Neurontin: peripheral edema, dizziness, myalgias, ataxia, mood swings, fatigue

Examination

This section is intended to capture the most commonly used assessment tools for this case type/diagnosis. It is not intended to be either inclusive or exclusive of assessment tools.

Observation:

- Skin: note appearance of skin: thin, taut, shiny, presence of fibrosis/hardness, color, presence of edema (pitting or non-pitting)
- Scars: appearance, location, color
- Wounds: size, location, color, drainage, dressing, sutures

Palpation/Skin and scar assessment:

- Assess overall skin tissue texture: note presence of scars and adhesions, describe the tissue quality: brawny and fibrous, soft and pliable, note the presence of orange peel texture, which may be present in patients with inflammatory breast cancer.
- Assess scar tissue: note location and size of scar, type of scar (hypertrophic, keloid, or widespread), texture (thick, rigid and raised or flattened and softened), presence of adhesions, and mobility of scar (poor, fair, good, or normal)

Limb girth:

- Compare affected extremity to non-affected extremity
- Use a tape measure at set marks on the skin. To achieve consistent and reliable measurements position the patient supine and position the tape measure with its distal border on the mark to be measured. The tape measure should be taut but not indenting or pulling on the skin.
 - For upper extremity measurements, mark the skin at the proximal tip of the ulnar styloid process and mark at every 5 cm proximally for the length of the arm.

- For the lower extremity measurements, mark the skin at the proximal tip of the lateral malleolus and then at every 10 cm proximally for the length of the leg.
- Use volumetric measurements, if available
- Record measurements using the lymphedema girth measurement form.
- Classifications of lymphedema using the American system⁶:
Mild 1.5-3.0 cm; Moderate 3.1-5.0 cm; Severe > 5.0 cm
- Grades or stages of lymphedema according to the International Society of Lymphology⁷
 - Grade I: pitting edema, partially reversible with elevation
 - Grade II: non-pitting edema, brawny skin, not reversible with elevation
 - Grade III: lymphostatic elephantitis, enormous swelling of the involved extremity, fibrosis and hardening of the dermal tissues, skin papillomas, acanthosis, fat deposits, and warty overgrowths may be present
- Within each stage, the severity can be based on limb volume compared to the non-affected limb:
 - Minimal: < 20% increase in limb volume
 - Moderate: 20-40% increase in limb volume
 - Severe: > 40% increase in limb volume
- For facial lymphedema, describe specific areas of increased swelling, note obstructed and visible facial bones

Height and Weight:

- Record the patient's height and weight and calculate the patient's Body Mass Index (BMI):

$$\frac{\text{Weight (pounds)}}{[\text{Height (inches)}]^2} \times 703 \quad \text{or} \quad \frac{\text{Weight (kg)}}{[\text{Height (m)}]^2}$$
- BMI online calculators can also be used to calculate BMI, e.g. www.nhlbisupport.com/bmi⁸
- Note recent changes in the patient's weight associated with the onset or change in severity of their lymphedema symptoms as a positive correlation has been described in the literature between BMI and the incidence of secondary lymphedema.⁹

Pain:

- Use body chart to record location of pain and other symptoms.
- Rate pain using the visual/verbal analog scale (VAS).
- Note aggravating and relieving factors for pain symptoms and functional limitations associated with pain

Posture/alignment:

- Note cervical/thoracic/lumbar spine alignment, shoulder and scapular alignment and LE alignment as appropriate.

Upper or Lower Quadrant Screen:

- Assess appropriate myotomes, dermatomes and reflexes.
- Further assess cervical or lumbar spine as needed.

Sensation:

- Assess light touch, pain, proprioception and stereognosis. The Semmes Weinstein can be used as appropriate to determine protective sensation in the involved limb.
- Expect posterior humeral and axillary numbness if a level 2 axillary dissection was performed as the intercostal brachial nerves are sacrificed during this procedure.

ROM:

- Assess A/PROM and note end feel as appropriate
- Consider the influence of postural alignment on ROM
- Consider how limited motion will challenge the effectiveness of the pumping mechanism of the lymph system. The initial lymphatic vessels lack a muscular layer and require the contractions of surrounding muscles to pump the lymph. A patient with impaired motion, therefore, will experience a decreased effectiveness of the muscle pumping action on the lymphatic system. Often mild lymphedema will resolve after ROM is restored.

Joint mobility:

- Assess glenohumeral capsular restrictions and scapular mobility as appropriate
- Assess LE joint mobility as appropriate given the specific areas of limitation and location of lymphedema
- Assess TMJ mobility as appropriate given presence of facial and neck lymphedema and patient reports with difficulty with mouth opening, chewing, talking, or other related symptoms.

Strength:

- Use MMT, Jamar Dynamometer and/or digital hand held dynamometer as appropriate.

Coordination:

- UE: consider hand-eye coordination and limb coordination as related to mobility and ADL tasks. Tests may include: rapid alternating movements, finger-to-nose, 9-hole pegboard, and the grooved pegboard tests. The clinician should start with gross motor coordination and progress to specific tests to further investigate deficits noted.
- LE: consider in terms of mobility, balance and ADL tasks. Tests may include rapid alternating movements, heel-to-shin and toe-tap-to-target.

Special Tests:

- There are no special tests designed specifically for lymphedema, however, often patients have concomitant shoulder pathology. Rule out impingement syndrome, rotator cuff tears, labral tears, acromioclavicular osteoarthritis, and other pathologies by using the appropriate clinical tests and refer back to MD for imaging as needed.
- Use LE special tests as appropriate given the patient's report of symptoms and clinical findings.

Cardiovascular Endurance:

- Assess vital signs including heart rate, blood pressure and oxygen saturation as appropriate. Consider the effect that mobilization of fluid has on the cardiovascular, respiratory and renal systems and monitor patients appropriately.

Cognition:

- Orientation.
- Memory: Include short-term memory deficits that can affect learning and carry over of therapy program
- Learning style: Include visual, verbal, written, and a combination to best meet the needs of the patient for long term carry over of therapy interventions
- Knowledge: Include knowledge of the signs and symptoms of lymphedema, treatment options, lymphedema prevention and risk factor reduction strategies, and long-term management and precautions individually tailored for each patient.

Functional Status:

- Assess how impairments and physical limitations impact independence with the following tasks:
 - Activities of daily living (ADL) including dressing, grooming, hygiene, and meal preparation
 - Instrumental activities of daily living (IADL) including housework and grocery shopping
 - Recreational activities
 - Vocational activities
- Assess compensatory strategies
- Use standardized outcome measures as appropriate. Consider using the Shoulder Pain and Disability Index (SPADI) for patients with UE lymphedema and Lower Extremity Functional Scale (LEFS) for patients with LE lymphedema

Differential Diagnosis:

Consider additional possibilities for an edematous limb:

- *Acute trauma or surgery.* Expect swelling for 6-8 weeks following trauma or surgery.

- *Recurrent or metastatic disease.* This needs to be ruled out for any development of lymphedema without an identifiable cause. Inquire about most recent medical oncology appointments and diagnostic tests.
- *Thrombophlebitis or deep vein thrombosis (DVT).* This needs to be ruled out if the patient presents with warmth, redness, discoloration, and pain to muscle palpation in the affected extremity.
- *Arterial insufficiency.* This needs to be ruled out if the patient presents with coldness, pallor, cold sensitivity, and stiffness in the affected extremity.
- *Congestive Heart Failure.* Rule out fluid overload due to cardiovascular compromise. A patient with CHF must be cleared by his or her cardiologist prior to initiating manual lymphatic drainage techniques as the shift in fluid balance will alter the effectiveness of the cardiovascular pump.
- *Chronic Venous Insufficiency, Venous Stasis, Varicose Veins.* Edema is present only in dependent positions. Refer the patient to a vascular surgeon for further work up.
- *Lipedema.* Swelling of unknown etiology with bilateral, symmetrical fatty deposits, usually from ankles to pelvis.

Assessment:

Establish Diagnosis and Need for Skilled Services

Patients with lymphedema often present with symptoms of fullness, tightness or heaviness in an extremity, altered sensation, and inability to wear rings, bracelets or other jewelry; and may report clothing feeling tight on the affected side. These patients may or may not have visible swelling of the affected extremity, but further evaluation may detect extremity girth differences. A difference of two centimeters or more at any measurement point, between the affected and non-affected extremity, warrants an occupational or physical therapy evaluation and subsequent treatment for lymphedema.¹⁰ Patients with less of a measurement difference between their extremities (sometimes referred to as pre-clinical lymphedema) will benefit from skilled therapy interventions as well, especially if they present with reduced ROM, strength, and/or functional limitations. Treatment is beneficial for any patient who is at risk for future development of lymphedema in order to become independent in risk reduction strategies and to initiate a home exercise program and to provide a safe, effective progression of their daily and/or recreational activities.

Problem List

Potential impairments include:

1. Pain
2. Increased limb size, girth and weight
3. Decreased scar mobility
4. Altered sensation
5. Loss of ROM
6. Impaired strength
7. Impaired skin integrity

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8. Impaired endurance
9. Impaired coordination
10. Impaired balance
11. Impaired gait
12. Decreased functional independence
13. Lack of knowledge about lymphedema, treatment and prevention strategies

Prognosis:

A patient's response to therapy intervention will depend on multiple factors including the medical treatment regimen utilized, number and type of surgeries performed, complications with medical or surgical treatment, severity of lymphedema, chronicity of symptoms, and the presence of recurrent disease or metastases, as well as individual patient factors including their lifestyle, daily activities, work responsibilities and adherence to the therapy home program.

The prognosis for improvement with physical and occupational therapy intervention has been investigated in several research studies and has shown promising results. A brief overview will follow.

Complete decongestive therapy (CDT), also referred to as Decongestive Lymphatic Therapy (DCT), which includes meticulous skin care, manual lymphatic drainage, exercise therapy, compression bandaging and compression garments, has been shown to be effective in the treatment of lymphedema. Ko and colleagues showed a 59% reduction in UE lymphedema and a 67% reduction in LE lymphedema following complete decongestive therapy for an average of 15-16 daily (or twice daily) treatment sessions.¹¹ They also showed an average of 90% maintenance of the improved limb volume over 9 months in subjects (86% of subjects) who were compliant with their home programs which consisted of wearing a daytime compression garment, nighttime bandaging, and continuation of a home exercise program.¹¹

Compression bandaging with short stretch bandages has been shown to be effective in reducing limb size when used alone,^{12,13,14} in combination with compression garments¹² and in combination with manual lymphatic drainage.^{13,14} The greatest limb volume reduction occurs in the first 2 weeks of treatment with compression wrapping¹³ and averaged between 26%¹³ and 38%¹⁴ volume reduction. Both groups also found that the addition of manual lymphatic drainage in combination with compression wrapping increased limb volume reduction by 7%¹³-7.5%¹⁴.

Multiple research studies have shown that various modes and intensity of exercise does not exacerbate lymphedema.^{15,16,17,18}

Elevation as a single treatment intervention does not significantly reduce lymphedema; it may, however, be an adequate treatment in combination with compression bandaging or garments for maintenance to prevent increases in lymphedema. In a study by Swedborg and others, a 1-3% volume reduction occurred after 1-5 hours of elevation.¹⁹

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In a study by Szuba and others in 2002, intermittent pneumatic compression used for 30 minutes/day for 10 days enhanced the initial volume reduction when used in conjunction with CDT.²⁰ In a 1998 study by Boris and colleagues, however, the researchers found that 43% of the patients who used the compression pump for treatment of their LE lymphedema developed genital lymphedema.²¹ Therefore, use intermittent pneumatic compression for the lower extremities with caution, and always assess for changes in genital lymphedema.

Researchers have also shown that the greatest reduction in limb volume with therapy intervention occurs in individuals with mild lymphedema.^{14,22} Educating patients to recognize early signs of lymphedema and seek early treatment, therefore, is advocated for this population.

Age Specific Considerations

Lymphedema can affect men and women of all ages. The most common type of lymphedema in the United States is secondary lymphedema, which most often occurs as the result of medical treatment, generally for cancer. Breast cancer can affect both men and women aged 20-90+, and its incidence is 100 times higher in women and increases with age.²³ According to the Breast Cancer Facts and Figures 2005-2006 from the American Cancer Society, 95% of new cases between 1998 and 2002 were in women aged 40 and older.²³ The presence of secondary lymphedema, therefore, would be expected to be seen in patients of all ages as well. All patients must be evaluated and treated based on their individual needs and ability to perform certain treatment techniques independently.

Goals

Short and long term goals to be met in 4-8 weeks may include but are not limited to:

1. Independence with home exercise program
2. Independence with compression bandaging
3. Independence with self massage techniques
4. Independence with lymphedema prevention and risk factor reduction strategies
5. Reduce limb girth by 25-50%
6. Maximize ROM
7. Maximize strength
8. Independence with postural correction in various positions
9. Maximize independence with functional activities

The timeframe for clinical improvement will vary depending on the individual patient and the severity of lymphedema and other coexisting impairments.

Treatment Planning / Interventions

Established Pathway ___ Yes, see attached. _X_ No

Established Protocol ___ Yes, see attached. _X_ No

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Interventions most commonly used for this case type/diagnosis.

This section is intended to capture the most commonly used interventions for this case type/diagnosis. It is not intended to be either inclusive or exclusive of appropriate interventions.

- Therapeutic exercise program including ROM, strengthening, and stretching
- Postural reeducation
- Manual lymphatic drainage
- Soft tissue mobilization/myofascial release
- Scar tissue management including cross friction massage, scar pads, kinesiotape
- Sensory reeducation and desensitization
- Compression bandaging
- Compression garment recommendations/prescription
- Compression pumps
- Home program for exercises, self massage, compression wrapping
- Patient education on lymphedema prevention or risk factor reduction
- Self care and home management training with instruction in task modification, compensatory techniques and pacing as appropriate
- Gait and balance training as appropriate
- Aquatic therapy (not available at BWH)

Frequency & Duration:

The frequency and duration of care will be dependent on individual patient's therapeutic needs as determined after a comprehensive evaluation. Consider the patient's ongoing medical treatments and the potential fatigue and side effects associated the treatments when determining frequency of therapy sessions. The frequency and duration may range from a one time visit for an assessment and education regarding lymphedema prevention to 2-3 visits per week for 6 or more weeks depending on the severity of lymphedema and associated impairment

Patient / family education

Instruct the patient and family:

- Lymphedema prevention and risk factor reduction techniques (handout available)
- Home exercise program (handouts available)
- Expected outcome of treatment and realistic goals
- Need for adherence to home exercise, self massage and compression program to maintain reduced limb volume and ROM of affected shoulder
- Available support groups and resources for patients depending on their individual need

Recommendations and referrals to other providers.

- Attending physician or surgeon: for any medical complications including suspicion of DVT or cellulitis

- Speech and Language Pathology: for patients with swallowing or speech difficulties associated with head and neck lymphedema
- Social Work or Psychiatry: for social issues and coping
- Nutritionist: for weight management and nutritional consultation
- Complimentary Medicine: may include the Zakim Center for Integrative Therapies at Dana Farber Cancer Institute for massage, acupuncture, Reike, nutritional support and other services
- Support Groups: American Cancer Society, National Lymphedema Network, Greater Boston Lymphedema Network

Re-evaluation / assessment

A formal reassessment should be completed every thirty days in the ambulatory care setting unless warranted sooner. For the acute setting, reassessment should be completed every 10 days unless needed sooner.

Possible triggers for an earlier reassessment include a significant change in medical status or symptoms, a visual change in limb size, sign of infection, or new trauma, as well as a plateau in progress and/or failure to respond to therapy.

Since limb volume can change significantly within a short time frame, girth measurements should be reevaluated more often than every 30 days. Limb measurements should be taken at least every 2 weeks in the ambulatory care clinics.

Discharge Planning

Commonly expected outcomes at discharge:

Discharge planning begins at the initial evaluation with patient and family education on the goals, treatment plan, prognosis and expected outcomes with therapy. The discharge plan is individualized for each patient and will include education on lifelong commitment to a home program, use of compression garments, self-massage/bandaging techniques and proper skin care for lymphedema prevention. Discharge from formal therapy will occur when the patient has met all of the established goals or has plateaued in their progress.

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