

An agency of the Provincial Health Services Authority

# Symptom Management Guidelines: LYMPHEDEMA

# Definition(s)

- **Lymphedema** is a condition in which protein-rich fluid accumulates in the tissues due to a failure of the lymphatic system. In cancer care it is most often associated with lymph node dissection and radiation therapy to lymph nodes. It can develop at any time between a few months and up to twenty years after treatment
- **Lymphorrhea**: Weeping of straw-colored lymph fluid which may lead to maceration and increase risk of infection (bacterial yeast, fungal)
- **Cellulitis**: Inflammation of tissue around a lesion that indicates an acute spreading infection of the skin, characterized by tenderness, swelling, redness

Appendix A: Assessment and Management of Cellulitis and Lymphorrhea

Contributing Factor	ors
Non-cancer Related	<ul> <li>Congenital and/or inherited abnormalities</li> <li>Trauma, surgery, filariasis (parasitic infection)</li> <li>Recurrent skin infections (e.g. cellulitis)</li> </ul>
Cancer- Related	<ul> <li>Tumor causing obstruction of lymphatic channels or nodes (e.g. intrapelvic or intra-abdominal)</li> <li>Breast cancer can cause upper-extremity lymphedema and breast and truncal edema</li> <li>Gynecological Cancers, Genitourinary Cancers, Lymphoma, Melanoma often associated with lower-extremity edema</li> <li>Sarcoma</li> <li>Head and Neck Cancers</li> <li>Colorectal Cancers</li> <li>All tumors have potential to cause lymphedema</li> </ul>
Cancer- treatment Related	<ul> <li>Radiation therapy to lymph nodes (i.e. axillary, inguinal, pelvic, or supraclavicular areas)</li> <li>Lymph node biopsy and/or dissection (greater risk with axillary node than sentinel node)</li> </ul>
Other	<ul> <li>Advanced age</li> <li>Inflammatory arthritis</li> <li>Post-operative infection and delayed wound healing</li> <li>Axillary web syndrome</li> <li>Accumulation of fluid at or near a surgical wound</li> <li>Surgical drains leaking protein into the surgical site</li> <li>Inflammation, infection, blood clot</li> <li>High BMI (&gt;29.5)</li> <li>Paralysis of affected limb</li> <li>Extreme environmental temperatures</li> <li>Sunburn, skin irritation, cuts, burns, insect or pet bites</li> <li>Air travel</li> </ul>

### Consequences

- Pain, depression, psychosocial implications
- Increased risk of skin infection (e.g. cellulitis)
- · ADL's and mobilization may be affected
- Disturbance of body image
- Financial implications

Appendix B: Complications of Lymphedema

#### **Focused Health Assessment** SYMPTOM ASSESSMENT **GENERAL** PHYSICAL ASSESSMENT **ASSESSMENT** Normal Contact & General Have you had any previous difficulties with limb **Vital Signs** Information swelling? Changes in sensation? Decreased As clinically indicated Physician name flexibility oncologist, family Usual activity level prior to cancer diagnosis? Observe patient's general physician appearance Pharmacy Onset Home health care When did it start? (i.e. suddenly or gradually over Inspection Other health care the last few days?) Observe posture: rounded providers (e.g. How long did previous episodes last, if any? shoulders, guarding or cradling physiotherapist, How often does it occur? of extremity massage therapist) Accessory muscles use, chest Has the swelling been intermittent or continuous? Allergies wall movement. Has there been progression over time? shape/abnormalities Does clothing or jewelry feel tighter or leave marks **Consider Contributing** Mobility, range of motion of on the skin of the affected limb? **Factors** nearest joint Cancer diagnosis Provoking / Palliating Observe skin color, pallor, and treatment(s) redness, wounds, discoloration, What triggered swelling? What makes it worse? ensure that there has What makes it better? Is it reduced in the morning? shininess. Shiny appearance been a recent Any recent trauma, puncture wounds, burns, bites? associated with more advanced physician or lymphedema Any heavy lifting, unusual or repetitive activity? oncologist follow-up Inspect for asymmetry, tautness, Any exposure to extreme heat? and they are aware of loss of normal skin folds Any recent prolonged travel? (flying or driving) onset of edema Peripheral edema – bilateral or Previous episodes of cellulitis, erysipelas or Recurrent cancer unilateral lymphangitis? must be ruled out Pitting or non-pitting edema-to DVT must be ruled test for pitting edema apply firm Quality out pressure to edematous tissue for Changes in comfort or sensation? Any pain, Note type and date of a minimum of 5 seconds) tightness, fullness, aching, heaviness, numbness, last radiation burning sensation? Itching? Generalized edema treatment Head, neck and truncal edema Surgical history: Region / Radiation Breast edema Number of lymph Pattern of development and progression (proximal-Abdominal ascites nodes removed, postdistal) Vein distention op infection, Marks left on skin from jewelry or prolonged healing or Severity clothing (e.g. bra straps, socks) other complications; How bothersome is this symptom to you? (on a and compare bilaterally any coronary artery scale of 0 - 10, with 0 not at all and 10 being the bypass or joint worst imaginable) **Palpation** surgery

### **Treatment**

- What do you do/ have you done when you notice upper/ lower limb swelling?
- What medications or other strategies? (i.e. exercise, physiotherapy, elevation compression sleeves, etc.) have you tried in the past? Now? How effective have these been? Any side effects?

## Understanding / Impact on You

- What have you been told about lymphedema?
- How does the presence of lymphedema affect you?
- How has this condition affected your activity?
- How does this affect your family?

- Turgor, warmth, texture of underlying tissues, presence of pittina
- Peripheral pulses
- Check for Stemmer's sign: In the advanced lymphedematous limb, a fold of skin cannot be pinched and lifted

#### Measurements

- Height and Weight
- Edema measurements (i.e. limb, head, neck, trunk)
- Perform measurements to

- Radiation history note type, location and time of treatment
- Medical historycardiac, renal, hepatic, hematological issues
- Previous trauma- to quadrant drained by regional lymph nodes (e.g. rotator cuff injury)
- Medication profile
- Review medical tests:

<ul> <li>Value</li> <li>What is your comfort goal or acceptable level for this symptom? (0 – 10 scale)</li> <li>Are you interested in receiving assistance in managing this condition?</li> <li>establish early onset and / or treatment effectiveness</li> <li>Use non-stretch measuring tape</li> <li>Document the position of the limb and measurements for future reference</li> </ul>			
NT - Continued			
Measure both limbs at predetermined intervals; start with unaffected side to establish			
baseline.			
• Difference of <b>2.0 cm</b> between affected and unaffected limb is considered clinically significant			
and indicative of lymphedema. Lymphedema starts before this difference is evident; many secondary and sometimes irreversible changes have already occurred by this time.			
With limb in supported position. Palm down and arm straight measure:			
<ul> <li>Circumference starting at mid hand and continue every 5-10 cm along the arm until 2 cm below the axilla.</li> </ul>			
Assess for truncal edema (lateral to breast and often extends to lateral boarder of scapula)			
<ul> <li>Assess for breast edema (most easily identified by marks from bra, skin pallor and fullness compared to non-affected side).</li> </ul>			
Patient to be supine, standing or sitting with foot flexed to 90 degrees measure:			
- Circumference starting at heel and continue every 5-10 cm along the leg until 2 cm			
below the popliteal fossa. If swelling exists above the knee, continue measurements to 2 cm below the gluteal crease			
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LYMPHEDEMA GRADING SCALE Adapted from NCI CTCAE (Version 4.03)				
Normal	GRADE 1 (Mild)	GRADE 2 (Moderate)	GRADE 3 (Severe)	GRADE 4 (Life - threatening)
Asymptomatic	Trace thickening or faint discoloration	Marked discoloration; leathery skin texture; papillary formation; limiting instrumental ADL(e.g. preparing meals, shopping, managing money)	Severe symptoms; limiting self care ADL (e.g. bathing, dressing, feeding self, using the toilet, taking medications)	_

For Further Grading See Appendix C: International Society of Lymphology (ISL) Lymphedema Scale

\*Step-Up Approach to Symptom Management: Interventions Should Be Based On Current Grade Level and Include Lower Level Grade Interventions As Appropriate

#### **NORMAL – GRADE 1**



# **NON-URGENT:**

Prevention, support, teaching & follow-up as clinically indicated

Prior to any treatment the presence of DVT, infection, cancer recurrence, or superior vena cava obstruction must be ruled out by a physician

Patient Care and Assessment

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- Ongoing assessment is necessary as the risk of lymphedema is lifelong
- Early intervention improves control of lymphedema

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Patient Education	<ul> <li>Ideal time to introduce lymphedema education would be pre and post surgery and post radiation therapy</li> <li>To limit severity of condition, encourage early recognition and reporting of signs of lymphedema and infection including: heaviness, tightness, discomfort, swelling, stiffness, change in sensation, redness, temperature, rash and flu-like symptoms. If experiencing these symptoms seek medical attention promptly.</li> <li>Avoid the following on affected side or site(s):         <ul> <li>Carrying heavy items</li> <li>Extreme temperatures (i.e. hot tubs) and application of heat to affected limb</li> <li>Blood pressure, venipuncture, glucose monitoring or injections</li> <li>Constrictive pressure (e.g. tight-fitting clothes, jewelry)</li> <li>Prolonged sitting, crossing legs and standing if lower extremity lymphedema</li> <li>Movements that cause repetitive strain</li> </ul> </li> <li>Air Travel Precautions:         <ul> <li>Encourage: Exercise, deep breathing, standing and moving every 30 minutes. Patients with upper extremity lymphedema may periodically squeeze a small ball in hand</li> <li>Maintain adequate fluid intake</li> <li>Avoid carrying or moving heavy luggage</li> <li>Individuals at risk and/or have experienced swelling, should wear an arm sleeve before, during and for several hours after travel to promote maximum lymphatic drainage. Patients with lower extremity lymphedema may wear compression garments at least to knee</li> </ul> </li> </ul>
Dietary Management	<ul> <li>Encourage healthy body weight</li> <li>Encourage low fat and salt- restricted diet</li> <li>No indication for restriction of oral fluids or protein intake to control lymphedema</li> </ul>
Therapeutic Exercise	<ul> <li>Deep breathing and regular activity enhances normal physiological processes involved in lymphatic transportation</li> <li>Encourage post operative stretching, range of motion and strengthening exercises as directed by surgical team</li> <li>Encourage slowly progressive exercises (i.e. resistance and strength training) including to the affected limb with careful monitoring</li> <li>If patient has compression garment, encourage that it be worn during exercise</li> </ul>
Limb Elevation	Elevation of limbs above heart level may decrease swelling in early stage
Skin and Nail Care	<ul> <li>Thorough skin and nail care is recommended to prevent an entry port for infection</li> <li>Inspect skin daily for any signs of infection, dermatitis, breakdown, redness and lymphorrhea; report symptoms to healthcare providers as early intervention is required</li> <li>Treat abrasion or small tears (i.e. paper cuts) immediately with a topical antibiotic</li> <li>Use mirror to examine hard to see areas with careful examination if neuropathy present</li> <li>Wash limb daily using pH neutral soap. Dry carefully, especially between fingers and toes</li> <li>Moisturize with unscented, water-based, low pH lotion. To prevent folliculitis, apply lotions using longitudinal strokes in a proximal to distal direction (follow direction of hair growth).</li> <li>Do not apply lotions directly before applying compression garment</li> <li>Avoid abrasive and perfumed products, adhesive bandages, and chemical hair removers</li> <li>Protect affected limb from sunburn, insect bites, pet scratches, injury</li> <li>Wear gloves during gardening, cooking, housework; avoid going barefoot</li> <li>Use only electric razors</li> </ul>



# **URGENT:**

# Requires medical attention within 24 hours

Any sudden and/ or new unilateral swelling must be assessed within 24 hours

Prior to any treatment the presence of DVT, infection, cancer recurrence, or superior vena cava obstruction must be ruled out by a physician			
Patient Care and Assessment	<ul> <li>Collaborate with physician to rule out other causes or concomitant causes of lymphedema and to determine if further investigation warranted</li> <li>Tests that may be ordered:         <ul> <li>CT scan, MRI, venous doppler, blood cultures, CBC</li> </ul> </li> </ul>		
Manual lymphatic drainage	A massage technique that uses light, superficial, and gentle strokes to mobilize edema fluid		
Compression Bandaging	<ul> <li>Multilayered padding and short-stretch bandages are applied to the affected limb which helps increase lymphatic flow</li> <li>Generally applied after manual lymphedema drainage is performed</li> </ul>		
Compression Garments	<ul> <li>Compression garments (e.g. lymphedema compression sleeve or stocking) promotes mobilization of edema fluid</li> <li>Recommended at first signs of swelling once assessment completed</li> <li>Should fit comfortably. Prescription indicating amount of pressure is required (often done by trained therapist): <a href="http://www.bclymph.org/Default.aspx?pageld=715840">http://www.bclymph.org/Default.aspx?pageld=715840</a>.</li> <li>Improper application can compress nerves or blood vessels and cause complications; pharmacies specializing in medical equipment with certified fitters recommended</li> <li>For best results, encourage use of garment during day and removal at night. Option to wear breast pad and/or purpose designed night garments overnight as prescribed to prevent tissue fibrosis.</li> <li>Replace garment every 3-6 months or when elasticity decreased</li> <li>Wash daily</li> <li>Custom garments are available for head, trunk and genital edema</li> <li>Supportive bras and compression tops for truncal edema</li> </ul>		
Intermittent Pneumatic Compression	An electrical air compression pump is attached to a plastic sleeve or stocking that is intermittently inflated over the affected limb		
Complex Decongestive Therapy	<ul> <li>Is a multimodality technique usually delivered in a two-phase program</li> <li>Phase I (treatment) includes: Skin and nail care, therapeutic exercise, manual lymphatic drainage, and limb compression with inelastic bandages to reduce limb volume</li> <li>Phase II (maintenance) includes: Compression garments, skin care continued therapeutic exercise and if necessary, manual lymphatic drainage. Night garments indicated if fibrosis present.</li> </ul>		
Subcutaneous Drainage	H:\EVERYONE\nursing\REFERENCES AND GUIDELINES\BCCA Nursing Practice  Reference Manual (S-60 Subcutaneous Drainage for the Management of Lower Extremity Edema)		
Pharmacologic Management	<ul> <li>Diuretics are not usually prescribed for lymphedema as edematous fluid is not easily shifted into the vascular space</li> <li>Antibiotic use for cellulitis. IV antibiotics may be required for severe cellulitis, lymphangitis or septicemia</li> </ul>		

RESOURCES & REFFERALS			
Referrals	<ul> <li>Emergency department or physician if suspected cellulitis</li> <li>Home Health Nursing</li> <li>GP</li> <li>Infectious disease specialists</li> <li>Wound care specialists</li> <li>Pain and Symptom Management/Palliative Care Program (PSMPC)</li> <li>Patient Support Centre or Telephone Care Management</li> <li>Patient and Family Counseling</li> <li>Physiotherapy and Occupational therapy</li> <li>Lymphedema specialist</li> <li>Certified fitters</li> </ul>		
Patient Education Resources	<ul> <li>www.bclymph.org/</li> <li>www.bcphysio.org</li> <li>www.massagetherapy.bc.ca</li> <li>www.canadalymph.ca         For compression garment fitters: <a href="http://www.bclymph.org/Default.aspx?pageld=962914">http://www.bclymph.org/Default.aspx?pageld=962914</a></li> <li>For therapists:         <a href="http://www.vodderschool.com/find_a_therapist">http://www.vodderschool.com/find_a_therapist</a> <a href="http://www.bclymph.org/Default.aspx?pageld=962912">http://www.bclymph.org/Default.aspx?pageld=962912</a></li> <li>For physiotherapy lymphedema programs:         <a href="http://www.bccancer.bc.ca/PPI/TypesofCancer/Breast/Rehabilitation/LocationofLymphapress-PhysiotherapyProgramsinBC.htm">http://www.bccancer.bc.ca/PPI/TypesofCancer/Breast/Rehabilitation/LocationofLymphapress-PhysiotherapyProgramsinBC.htm</a></li> <li>Exercise clinics: <a href="http://www.bclymph.org/Default.aspx?pageld=1544579">http://www.bccancer.bc.ca/PPI/TypesofCancer/Breast/Rehabilitation/default.htm</a></li> <li>Aguide for women with lymphedema:         <a href="http://www.bccancer.bc.ca/PPI/TypesofCancer/Breast/Rehabilitation/default.htm">http://www.bccancer.bc.ca/PPI/TypesofCancer/Breast/Rehabilitation/default.htm</a></li> <li>American Cancer Society- Lymphedema: What Every Woman With Breast Cancer Should Know <a href="http://www.cancer.org/acs/groups/cid/documents/webcontent/002876-pdf">http://www.cancer.org/acs/groups/cid/documents/webcontent/002876-pdf</a></li> <li>American Cancer Society- Understanding Lymphedema: For Cancers Other Than Breast Cancer <a href="http://www.cancer.org/acs/groups/cid/documents/webcontent/002928-pdf.pdf">http://www.cancer.org/acs/groups/cid/documents/webcontent/002928-pdf.pdf</a></li> <li>Pharmacare coverage for upper extremity lymphedema: <a href="http://www.health.gov.bc.ca/pharmacare/pins/prospins.html">http://www.health.gov.bc.ca/pharmacare/pins/prospins.html</a></li> </ul>		
Related Online Resources	E.g. Fair Pharmacare; BC Palliative Benefits <a href="http://www.bccancer.bc.ca/NR/rdonlyres/AA6B9B8C-C771-4F26-8CC8-47C48F6421BB/66566/SymptomManagementGuidelinesRelatedResources.pdf">http://www.bccancer.bc.ca/NR/rdonlyres/AA6B9B8C-C771-4F26-8CC8-47C48F6421BB/66566/SymptomManagementGuidelinesRelatedResources.pdf</a>		
Bibliography List	http://www.bccancer.bc.ca/HPI/Nursing/References/SystemManagementGuidelines/Biblio.htm		

# Appendix A: Assessment and Management of Cellulitis and Lymphorrhea

Cellulitis	*Prompt treatment is critical to avoid the development of tissue damage that predisposes patient to repeated episodes of infection and worsening lymphedema  Assessment: Onset may be over minutes to weeks with systemic symptoms:  Swelling, skin red, warm or hot, tender to touch  More severe cases: fevers, chills, rigor, high fever, headache, vomiting malaise, decreased appetite  Skin rashes may be present  Management:  Prior to prescribed antibiotic treatment:  Mark and date the edge of erythema  Establish presence and location of enlarged, tender lymph nodes  *If episodes of cellulitis occur more than twice per year, patient may require prophylactic antibiotics
Lymphorrhea	<ul> <li>If seepage of lymph fluid occurs, layers of absorbent dressings are required to prevent skin</li></ul>
Management	maceration and breakdown

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- Protect surrounding skin with lotion and apply a non-adherent, absorbent dressing
- Use a sterile thick dressing for 24-48 hours until leakage is resolved
- Dressings may require changing up to four or more times per day to prevent maceration

# **Appendix B: Complications of Lymphedema**

Chronic Dermatitis	Inflammation of the epidermis and dermis of the skin			
Hyperkeratosis	Patches of hard, reptile-like, thickened skin			
Fibrosis	Thickened, brawny, leathery appearance due to connective tissue scarring			
Cracks/ Fissures	Portal for staph/ strep infections as lymph vessels cannot drain away microbes that colonize or penetrate skin			
Lymphangitis	Inflammation of the lymphatic channels resulting from infection at a site distal to the channel			
Lymphangiectasia	Blister –like lesions caused by dilatation of upper dermal lymphatic vessels- occur anywhere on lymphedematous limb, most commonly in areas of subcutaneous fibrosis (i.e. radiation treatment site). May progress to papillomatosis			
Papillomatosis	Skin has rough, cobblestone appearance and texture- engorged, raised lymph vessels on surface			
Reflex sympathetic dystrophy	A progressive and potentially disabling and extremely painful condition affecting nerves, skin, muscles, blood vessels and bones. Hallmarks include unexplained edema, burning pain, and temperature changes. Dystrophy may occur later.			
Secondary Malignancies	Squamous cell, lymphoma, melanoma and malignant fibrous histiocytoma have been associated with lymphedema (Lymphangiosarcoma-most common). Impaired local immunosurveillance is thought to be a causative factor.			
Lymphangiosarcoma (Stewart-Treves Syndrome)	This potentially fatal, rare consequence of uncontrolled lymphedema for > 10 years, and chronic tissue infections presents as purple-red patches and bumps on the skin of the lymphedematous area. All lesions should be biopsied.			
Delayed Wound Healing	Lymphedema causes pressure on blood vessels, decreasing circulation to the affected area. This causes a degree of ischemia, reduces the delivery of oxygen and nutrients and also inhibits the removal of cellular waste products. Increase in the colloidal proteins leads to stagnation of fluids and proteins and eventually fibrosis of connective tissues. This in turn predisposes the individual to infections which also contributes to fibrosis in the edematous limb.			

# Appendix C: International Society of Lymphology (ISL) Lymphedema Scale

LYMPHEDEMA SCALE International Society of Lymphology (ISL)				
Stage 0 (Sub-clinical)	Stage 1 (Early/Mild)	Stage 2 (Moderate; requiring compression))	Stage 3 (Severe; limiting function)	Stage 4 (Severe; limiting function with ulceration)
<ul> <li>Impaired lymph transport</li> <li>Asymptomatic</li> <li>Can remain in this stage for many years</li> <li>* Edema is usually not detectable until interstitial volume is approximately 30% above normal</li> </ul>	<ul> <li>Edema may be present intermittently, resolve without treatment.</li> <li>Little or no pitting or limb distortion</li> <li>2-3 cm difference in limb circumference, complaints of feeling of</li> </ul>	<ul> <li>Early: <ul> <li>3-5 cm difference in limb circumference</li> <li>Skin may be shiny, stretched, fragile</li> <li>Significant limb distortion;</li> <li>May have difficulty buttoning sleeves, fitting into shoes. Unable to tolerate compression garment.</li> </ul> </li> </ul>	<ul> <li>Greater than 5 cm difference in limb circumference</li> <li>No pitting, poor skin turgor- feels firm (fibrosis)</li> <li>Skin thickening</li> <li>Increased skin folds, fat deposits</li> <li>May be discolored-purple or brownish</li> <li>Peau d'orange</li> </ul>	Massive distortion     Very high risk for cellulitis

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tightness, heaviness, fullness, stiffness.  • Able to tolerate compression garments	<ul> <li>Pitting of tissue for up to twenty minutes following gentle pressure</li> <li>Positive Stemmer's</li> </ul>	<ul> <li>Indurosis</li> <li>Distortion of limb- may swell to 1.5- 2.0 times normal size</li> </ul>	
gaments	sign Late:  Swelling not relieved by elevation  Non-pitting, brawny edema may also be present- due to chronic inflammation, tissue fibrosis  Hyperkeratosis, papillomatosis lymphorrhea may also be present	Lymphorrhea (weeping) maybe present	

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