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***

FOCUSED HEALTH ASSESSMENT

PHYSICAL ASSESSMENT

Vital Signs
As clinically indicated

Observe patient's general appearance

Inspection
- Observe posture: rounded shoulders, guarding or cradling of extremity
- Accessory muscles use, chest wall movement, shape/abnormalities
- Mobility, range of motion of nearest joint
- Observe skin color, pallor, redness, wounds, discoloration, shininess. Shiny appearance associated with more advanced lymphedema
- Inspect for asymmetry, tautness, loss of normal skin folds
- Peripheral edema – bilateral or unilateral
- Pitting or non-pitting edema-to test for pitting edema apply firm pressure to edematous tissue for a minimum of 5 seconds)
- Generalized edema
- Head, neck and truncal edema
- Breast edema
- Abdominal ascites
- Vein distention
- Marks left on skin from jewelry or clothing (e.g. bra straps, socks) and compare bilaterally

Palpation
- Turgor, warmth, texture of underlying tissues, presence of pitting
- 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 establish early onset and / or treatment effectiveness
- Use non-stretch measuring tape
  Document the position of the limb and

SYMPTOM ASSESSMENT

***Consider contributing factors**

Normal
- Have you had any previous difficulties with limb swelling? Changes in sensation? Decreased flexibility
- Usual activity level prior to cancer diagnosis?

Onset
- When did it start? (i.e. suddenly or gradually over the last few days?)
- How long did previous episodes last, if any?
- How often does it occur?
- Has the swelling been intermittent or continuous? Has there been progression over time?
- Does clothing or jewelry feel tighter or leave marks on the skin of the affected limb?

Provoking / Palliating
- What triggered swelling? What makes it worse? What makes it better? Is it reduced in the morning? Any recent trauma, puncture wounds, burns, bites? Any heavy lifting, unusual or repetitive activity?
- Any exposure to extreme heat?
- Any recent prolonged travel? (flying or driving)
- Previous episodes of cellulitis, erysipelas or lymphangitis?
- Previous history of blood clots or DVT?

Quality
- Changes in comfort or sensation? Any pain, tightness, fullness, aching, heaviness, numbness, burning sensation? Itching?

Region / Radiation
- Pattern of development and progression (proximal-distal)

Severity
- How bothersome is this symptom to you? (on a scale of 0 – 10, with 0 not at all and 10 being the worst imaginable)

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?

measurements for future reference	**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? **Value** • What is your comfort goal or acceptable level for this symptom? (0 – 10 scale) • Are you interested in receiving assistance in managing this condition?
PHYSICAL ASSESSMENT CONT.	
Limb Edema Measurement	• **Measure both limbs at predetermined intervals; start with unaffected side to establish baseline.** • **Difference of 2.0 cm 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.**
Upper extremity limb measurement	• **With limb in supported position. Palm down and arm straight measure:** - **Circumference starting at mid hand, wrist, mid fore-arm, elbow, mid upper arm, under the axilla** • **Assess for truncal edema (lateral to breast and often extends to lateral boarder of scapula)** • **Assess for breast edema (most easily identified by marks from bra, skin pallor and fullness compared to non-affected side).**
Lower extremity limb measurement	• **Patient to be supine, standing or sitting with foot flexed to 90 degrees measure:** - **Circumference starting at heel, mid calf, knee, 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**

LYMPHEDEMA GRADING SCALE

NCI Common Terminology Criteria for Adverse Events (CTCAE) **(Version 5.0)**

GRADE 1 (Mild)	GRADE 2 (Moderate)	GRADE 3 (Severe)	GRADE 4	GRADE 5
Trace thickening or faint discoloration	Marked discoloration; leathery skin texture; papillary formation; limiting instrumental ADL	Severe symptoms; limiting self care ADL	-	-

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

GRADE 1

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NON – URGENT:

Prevention, Support, teaching & follow-up care as required

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	– The risk of lymphedema is greatest within 3 years of lymph involving surgery or radiation therapy, although ongoing assessment are necessary as the risk persists indefinitely – Early intervention improves control of lymphedema – Patient education is key in early detection
Patient Education	• Ideal time to introduce lymphedema education would be pre and post surgery and post radiation therapy • 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. • At risk individuals should perform self-assessments and report changes in size, sensation, color, temperature or skin condition • Avoid the following on affected side or site(s): - Carrying heavy items - Extreme temperatures (i.e. hot tubs) and application of heat to affected limb - Blood pressure, venipuncture, glucose monitoring or injections - Constrictive pressure (e.g. tight-fitting clothes, jewelry) - Prolonged sitting, crossing legs and standing if lower extremity lymphedema - Movements that cause repetitive strain • Air Travel Precautions: - Encourage: Exercise, deep breathing, standing and moving every 30 minutes. Patients with upper extremity lymphedema may periodically squeeze a small ball in hand - Maintain adequate fluid intake - Avoid carrying or moving heavy luggage – 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
Healthy Lifestyle Promotion	• Dietary Management – Encourage healthy body weight – Encourage low fat and salt-restricted diet – No indication for restriction of oral fluids or protein intake to control lymphedema – Consult with a Registered Dietician for help with attaining a healthy BMI • Therapeutic Exercise – Prophylactic/early exercise and physiotherapy offer additional benefit and are generally recommended – Deep breathing and regular activity enhances normal physiological processes involved in lymphatic transportation – Encourage post-operative stretching, range of motion and strengthening exercises as directed by surgical team – Encourage slowly progressive exercises (ie. Resistance and strength training) including to the affected limb with careful monitoring – If patient has compression garment, encourage that it be worn during exercise

Infection Prevention	• Skin and Nail Care – Thorough skin and nail care is recommended to prevent an entry port for infection – Treat abrasion or small tears (i.e. paper cuts) immediately with a topical antibiotic – Use mirror to examine hard to see areas with careful examination if neuropathy present – Wash limb daily using pH neutral soap. Dry carefully, especially between fingers and toes – 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). – Do not apply lotions directly before applying compression garment – Avoid abrasive and perfumed products, adhesive bandages, and chemical hair removers – Protect affected limb from sunburn, insect bites, pet scratches, injury – Wear gloves during gardening, cooking, housework; avoid going barefoot – Use only electric razors • Recognize the signs and symptoms of infection – Fever – Inspect skin daily for dermatitis, breakdown, redness, lymphorrhea, pain and warmth; report symptoms to healthcare providers as early intervention is required
Independent Care Techniques	• Limb elevation – Elevation of limbs above heart level may decrease swelling in the early stage • Simple lymphatic drainage – Self-directed and self-performed massage techniques may help facilitate lymphatic drainage

URGENT – GRADE 2 and GRADE 3

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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	• Collaborate with physician to rule out other causes or concomitant causes of lymphedema and to determine if further investigation warranted • Tests that may be ordered: CT scan, MRI, venous doppler, blood cultures, CBC
Manual Lymphatic Drainage (MLD)	• A massage technique that uses light, superficial, and gentle strokes to mobilize edema fluid and encourage its recirculation back to the blood circulatory system • Initially done by a Registered Massage Therapist, but techniques can be taught for patient to perform to self at home
Compression Bandaging	• Multilayered padding and short-stretch bandages are applied to the affected limb which helps increase lymphatic flow – Generally applied after manual lymphedema drainage is performed

Compression Garments	• Should be assessed and prescribed by a trained therapist • Compression garments (e.g. lymphedema compression sleeve or stocking) promotes mobilization of edema fluid • Recommended at first signs of swelling once assessment completed • Should have high stiffness, but tolerable resting pressure to ensure a comfortable fit and increase adherence. Prescription indicating amount of pressure is required (often done by trained therapist) • Should be accompanied with adequate skin care, exercise and MLD • Improper application can compress nerves or blood vessels and cause complications; pharmacies specializing in medical equipment with certified fitters recommended • 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. • Replace garment every 3-6 months or when elasticity decreased • Wash daily • Custom garments are available for head, trunk and genital edema • Supportive bras and compression tops for truncal edema
Intermittent Pneumatic Compression	• An electrical air compression pump is attached to a plastic sleeve or stocking that is intermittently inflated over the affected limb • May be beneficial in addition to complex decongestive therapy
Complex Decongestive Therapy	• Is a multimodality technique usually delivered in a two-phase program • Phase I (Treatment/Active Phase) includes: Skin and nail care, therapeutic exercise, manual intensive lymphatic drainage and limb compression with multi-layer compression bandaging with varying degree of compression, additional materials and support materials (e.g. foam, wool). – Phase I is done with specially lymphedema trained physical or occupational therapists – Lasts 2-12 weeks depending on the amount of swelling and tissue firmness – Compression is maintained for 21-23 hours per day in this phase • Phase II (Maintenance Phase) includes: Compression garments, continued skin care and therapeutic exercise, self-administered lymphatic massage. Night garments indicated if fibrosis is present – Phase II is at home- care with self-directed continuation of the exercises and should only be implemented after phase I is complete
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Pharmacologic Management	• Diuretics are not usually prescribed for lymphedema as edematous fluid is not easily shifted into the vascular space • Antibiotic use for cellulitis. IV antibiotics may be required for severe cellulitis, lymphangitis or septicemia • Antimicrobial dressings for wounds/lymphorrea and weeping • Prompt topical antibacterial ointment (ie. Polysporin) for small cut or skin abrasions

RESOURCES & REFFERALS	
Referrals	• Emergency department or physician if suspected cellulitis • Home Health Nursing • GP • Infectious disease specialists • Wound care specialists • Pain and Symptom Management/Palliative Care Program (PSMPC) • Patient Support Centre or Telephone Care Management • Patient and Family Counseling • Physiotherapy and Occupational therapy • Lymphedema specialist • Certified fitters
Patient Education Resources	• www.bclymph.org/ • www.bcphysio.org • www.massagetherapy.bc.ca • www.canadalymph.ca http://www.bccancer.bc.ca/health-info/types-of-cancer/breast-cancer/lymphedema For compression garment fitters: https://www.bclymph.org/Online-Professional-Directory • For therapists: https://www.bclymph.org/Online-Professional-Directory • For a list of Certified RMT's for MLD and CDT: https://vodderschool.com/contacts/search • A guide for women with lymphedema: For exercise and rehabilitation recommendations-immediately post-op and ongoing: http://www.bccancer.bc.ca/health-info/types-of-cancer/breast-cancer/exercises-after-surgery • Patient Teaching Handout: http://www.bccancer.bc.ca/health-info/coping-with-cancer/managing-symptoms-side-effects/arm-leg-lymphedema-(swelling) • A guide for women with lymphedema: http://www.bccancer.bc.ca/health-info/types-of-cancer/breast-cancer/exercises-after-surgery • Pharmacare coverage for upper extremity lymphedema: https://www2.gov.bc.ca/gov/content/health/health-drug-coverage/pharmacare-for-bc-residents/what-we-cover/medical-supplies-coverage/prostheses?keyword=lymphedema
Related Online Resources	• E.g. Fair Pharmacare; BC Palliative Benefits. Can be found in "Other Sources of Drug Funding Section" http://www.bccancer.bc.ca/health-professionals/professional-resources/pharmacy/drug-funding
Bibliography List	• http://www.bccancer.bc.ca/health-professionals/clinical-resources/nursing/symptom-management

Contributing Factors	
Cancer- Related	• Tumor causing obstruction of lymphatic channels or nodes (e.g. intrapelvic or intra-abdominal) • Breast cancer can cause upper-extremity lymphedema and breast and truncal edema • Gynecological Cancers, Genitourinary Cancers, Lymphoma, Melanoma often associated with lower-extremity edema • Sarcoma • Head and Neck Cancers • Colorectal Cancers • All tumors have potential to cause lymphedema
Non-Cancer Related	• Congenital and/or inherited abnormalities • Trauma, surgery, filariasis (parasitic infection) – Recurrent skin infections (e.g. cellulitis)
Cancer- Treatment Related	• Radiation therapy to lymph nodes (i.e. axillary, inguinal, pelvic, or supraclavicular areas) • Lymph node biopsy and/or dissection (greater risk with axillary node than sentinel node)
Other	• Advanced age • Inflammatory arthritis • Post-operative infection and delayed wound healing • Axillary web syndrome • Accumulation of fluid at or near a surgical wound

	• Surgical drains leaking protein into the surgical site • Inflammation, infection, blood clot • High BMI (>29.5) • Paralysis of affected limb • Extreme environmental temperatures • Sunburn, skin irritation, cuts, burns, insect or pet bites • Air travel

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, loss of ability to work

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
	• Appropriate antibiotic treatment
	
	*If episodes of cellulitis occur more than twice per year, patient may require prophylactic antibiotics

Lymphorrhea Management	• If seepage of lymph fluid occurs, layers of absorbent dressings are required to prevent skin maceration and breakdown • 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)**
• Impaired lymph transport • Asymptomatic • Can remain in this stage for many years * Edema is usually not detectable until interstitial volume is approximately 30% above normal	• Edema may be present intermittently, resolve without treatment. • Little or no pitting or limb distortion • 2-3 cm difference in limb circumference, complaints of feeling of tightness, heaviness, fullness, stiffness. • Able to tolerate compression garments	**Early:** • 3-5 cm difference in limb circumference • Skin may be shiny, stretched, fragile • Significant limb distortion; • May have difficulty buttoning sleeves, fitting into shoes. Unable to tolerate compression garment. • Pitting of tissue for up to twenty minutes following gentle pressure • Positive Stemmer's 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	• Greater than 5 cm difference in limb circumference • No pitting, poor skin turgor- feels firm (fibrosis) • Skin thickening • Increased skin folds, fat deposits • May be discolored-purple or brownish • Peau d'orange • Indurosis • Distortion of limb-may swell to 1.5-2.0 times normal size • Lymphorrhea (weeping) maybe present	• Massive distortion • Very high risk for cellulitis

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