Lymphedema

Clinical summary of the ONS Guidelines™ for cancer treatment–related lymphedema

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Secondary (acquired) lymphedema is a chronic condition lacking a known cure that most commonly results from cancer treatment, particularly for breast, gynecologic, prostate, and head and neck cancers; lymphoma; and melanoma, and affects an estimated 1 in 1,000 Americans. Lymphedema is characterized by an accumulation of protein-rich lymphatic fluid in the affected part of the body. It can potentially affect functioning, family roles and relationships, occupational roles, and productivity. The majority of strategies to prevent and manage lymphedema are nonpharmacologic, used alone or in combination with one another.

Guideline Questions and Target Audience

What are the conservative (nonsurgical) interventions to identify lymphedema at an early stage, minimize the risk of progression to later stages, and treat lymphedema once present? The questions for this guideline fall into three main categories: prospective surveillance, risk reduction (risk of progression to later stages of lymphedema), and management. The target audience for this guideline are clinicians who care for individuals at risk for or diagnosed with lymphedema, policymakers, and patients and their caregivers.

How the Guideline Was Developed

This guideline was developed by an interprofessional panel of healthcare professionals, a methods expert, and a patient representative. The panel prioritized clinical questions related to secondary lymphedema and patient outcomes identified as critical for decision making. A systematic review and network meta-analysis of the literature was conducted to inform the clinical questions. The GRADE (Grading of Recommendations, Assessment, Development, and Evaluation) approach was used to assess the certainty of the evidence and provide a foundation for recommendations (Guyatt et al., 2011).

Why the Guideline Matters

Secondary lymphedema is associated with surgery and radiation therapy across a wide spectrum of cancer diagnoses. Breast cancer has the greatest prevalence, with an estimated 10%–40% of patients developing lymphedema. About 280,000 new breast cancer cases are predicted in 2020, which could result in thousands of patients diagnosed with lymphedema (American Cancer Society, 2020; Armer & Stewart, 2010).
Lymphedema can have physical, psychosocial, and financial effects on patients. The presence of lymphedema can be physically distressing and is associated with feelings of heaviness and difficulty. In addition, lymphedema can cause distress beyond physical symptoms and have a negative impact on psychosocial health and body image. Such distress may also be linked to social isolation and changes in the individual’s productivity, which may have an overall negative effect on the patient’s quality of life (Vignes et al., 2020).

Cancer survivors with lymphatic systems damaged by cancer treatment are at a lifetime risk of developing lymphedema. This risk, coupled with the chronicity of lymphedema once it develops and the potential effect it may have on the patient, highlights the importance of evidence-based strategies for reducing the risk of developing later stages of lymphedema and for managing lymphedema.

**Clinical Practice Recommendations**

**Prophylactic Massage**

The ONS Guidelines panel suggests prophylactic massage of postsurgical scar tissue by the patient for adults at risk for lower extremity lymphedema. This should not start until four to six weeks postsurgery to allow for wound healing. The panel noted that this massage should be guided and taught by a certified lymphedema therapist to ensure proper technique and to monitor progress. After such monitoring, patients and/or caregivers can then self-administer.

**Clinical Practice Recommendations**

**Prospective Surveillance**

Prospective surveillance includes structured pre- and postoperative care with a goal of identifying subclinical or early stages of lymphedema. Components of a surveillance program can vary but often include patient education, limb volume measurement, quality-of-life assessment, and physical examination (Ostby et al., 2014). The ONS Guidelines panel suggests prospective surveillance for adult patients who have had cancer-related surgery and are at risk for lymphedema. Integrating prospective surveillance as a component of routine pre- and postoperative visits, as well as survivorship visits, is important for patient acceptance.

**Risk Reduction**

The ONS Guidelines panel considers risk reduction to include minimization of risk or delay in developing secondary lymphedema, while noting that patients have a lifetime risk of lymphedema following cancer surgery. Exercise for risk reduction of lymphedema can be divided into two main subgroups: (a) delayed versus early exercise and (b) programmed versus no programmed exercise. The ONS Guidelines panel suggests that exercise initiation be delayed for at least seven days following surgery for adult patients with cancer who are at risk for extremity/trunkal lymphedema from cancer surgery. After postoperative recovery, the ONS Guidelines panel suggests programmed (i.e., supervised) exercise, including resistance and strengthening exercises, for adults who are at risk for extremity/trunkal lymphedema from cancer surgery. This exercise should start after a favorable physical assessment from the patient’s surgeon; a lymphedema therapist can provide guidance for types of exercise and monitor progress. To find a certified lymphedema specialist, visit www.clt-lana.org/search/therapists.

**“Nurses can educate patients and caregivers about signs of lymphedema to aid in early detection.”**

For adults at risk for lower extremity lymphedema, the ONS Guidelines panel suggests the use of compression garments to minimize or delay lymphedema development. Some patients may prefer not to wear compression garments because of discomfort or appearance concerns. For patients at risk for truncal, upper extremity, or head and neck lymphedema, prophylactic use of compression garments is suggested only in the context of a clinical trial.

Prophylactic massage of postsurgical scar tissue by the patient is suggested by the ONS Guidelines panel in adults with cancer at risk for developing lymphedema. This should not start until four to six weeks postsurgery to allow for wound healing. The panel noted that this massage should be guided and taught by a certified lymphedema specialist to ensure proper technique and to monitor progress. After such monitoring, patients and/or caregivers can then self-administer.

**Treatment**

The standard of care for treatment of lymphedema is complete decongestive therapy (CDT). CDT includes intensive lymphedema therapy (phase 1 of CDT) with a certified lymphedema therapist, followed by long-term self-management (phase 2 of CDT) administered by the patient and/or a caregiver. CDT includes meticulous skin and nail care, range-of-motion exercises, lymphatic drainage, and compression garments or bandages. Phase 2 of CDT includes all of these interventions but is performed by the patient with the assistance of a pump in some cases. Follow-up includes maintenance of self-care practices and assessment of soft tissue changes, which requires alterations in the self-care plan (Deng et al., 2019).

Incorporating an active treatment intervention in addition to self-management (phase 2 of CDT) of lymphedema is suggested by the ONS Guidelines panel for adult patients with secondary lymphedema. Active treatment interventions include aerobic, resistance, and water-based and yoga exercise, as well as manual lymphatic drainage, compression pumps, and combinations of these interventions. Compression pumps have a small potential for harm and can be a cost burden, so the ONS Guidelines panel...
## LYMPHEDEMA

### TABLE 1.
SUMMARY OF RECOMMENDATIONS: ONS GUIDELINES™ FOR CANCER TREATMENT–RELATED LYMPHEDEMA

<table>
<thead>
<tr>
<th>RECOMMENDATION</th>
<th>STRENGTH OF RECOMMENDATION</th>
<th>CERTAINTY OF EVIDENCE</th>
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<tbody>
<tr>
<td><strong>Prospective surveillance</strong></td>
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<tr>
<td>Recommendation 1: Among patients who have had cancer-related surgery, the ONS Guidelines panel suggests prospective surveillance, including an educative component, rather than no prospective surveillance, for detection of lymphedema.</td>
<td>Conditional</td>
<td>Very low</td>
</tr>
<tr>
<td>Remarks: Patients undergoing surgery who have a higher baseline risk for development of lymphedema may place greater value on participating in prospective surveillance programs and less value on the resources required to participate in such programs. In addition, patients may have a greater acceptance of prospective surveillance programs when institutions and practices integrate prospective surveillance components into regular pre- and postoperative care and wellness visits throughout survivorship.</td>
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<td><strong>Risk reduction</strong></td>
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<td>Recommendation 2a: Among patients with cancer who are at risk of extremity/truncal lymphedema from cancer surgery, the ONS Guidelines panel suggests delaying the initiation of programmed (supervised) exercise for at least 7 days following surgery (immediately after surgery).</td>
<td>Conditional</td>
<td>Very low</td>
</tr>
<tr>
<td>Recommendation 2b: Among patients with cancer who are at risk for extremity/truncal lymphedema from cancer surgery, the ONS Guidelines panel suggests initiating programmed (supervised) exercise, including resistance and strengthening, rather than no programmed exercise following the postoperative seven-day period and following a favorable physical assessment by the patient’s surgeon and lymphedema therapist.</td>
<td>Conditional</td>
<td>Low</td>
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<tr>
<td>Recommendation 3a: Among patients with cancer who are at risk for lower extremity lymphedema, the ONS Guidelines panel suggests the use of compression garments rather than no use of compression garments to delay or minimize the risk of lymphedema development.</td>
<td>Conditional</td>
<td>Very low</td>
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<tr>
<td>Remarks: Patients placing greater value on avoiding the appearance or discomfort of wearing compression garments for risk reduction may prefer to not wear them to delay or minimize risk because of smaller potential benefit.</td>
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<tr>
<td>Recommendation 3b: Among patients with cancer who are at risk for truncal, upper extremity, or head and neck lymphedema, the ONS Guidelines panel recommends the use of compression garments to delay or minimize the risk for lymphedema development only in the context of a clinical trial.</td>
<td>Knowledge gap</td>
<td>–</td>
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<td>Recommendation 4: Among patients with cancer at risk for extremity, truncal, or head and neck lymphedema, the ONS Guidelines panel suggests massage of postsurgical scar tissue rather than no massage of postsurgical scar tissue.</td>
<td>Conditional</td>
<td>Very low</td>
</tr>
<tr>
<td>Remarks: Massage of the scar tissue may be uncomfortable or painful and should be initiated only after recovery from acute tissue injury by a trained lymphedema therapist who can teach patients proper technique. If pain is too intense or for patients valuing to not experience pain during the massage, they may choose not to do this.</td>
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<tr>
<td><strong>Treatment</strong></td>
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<td>Recommendation 5: Among patients with cancer treatment–related secondary lymphedema, the ONS Guidelines panel suggests an active treatment intervention (MLD, compression pumps, resistance exercise, aerobic plus resistance exercise, water-based or yoga exercise, CDT plus resistance exercise, CDT plus compression pumps, or CDT plus compression pumps plus aerobic and resistance exercise) in addition to self-management (phase 2 CDT) rather than self-management alone.</td>
<td>Conditional</td>
<td>Very low</td>
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<tr>
<td>Remarks: Because of the potential for small harms, burden, and comparative cost of compression pumps, patients may wish to try other conservative treatments before compression pumps.</td>
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<tr>
<td>Recommendation 6: Among patients with cancer treatment–related secondary lymphedema, the ONS Guidelines panel suggests resistance exercises in addition to self-management rather than self-management alone.</td>
<td>Conditional</td>
<td>Very low</td>
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<tr>
<td>Remarks: Preference for resistance exercises may be driven by cost and accessibility.</td>
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remarked that patients may wish to try other interventions before compression pumps.

The ONS Guidelines panel suggests resistance exercises in addition to self-management (phase 2 of CDT) for patients with cancer treatment–related secondary lymphedema. Resistance exercise is generally well tolerated and accepted by patients, but guidance from a trained professional is important to teach patients the proper technique and how to gradually increase resistance.

The ONS Guidelines panel suggests water-based and yoga exercise in addition to self-management (phase 2 of CDT) for adults at risk for cancer treatment–related secondary lymphedema. Patient preference for and engagement with water-based and yoga exercise may be influenced by the cost and accessibility of these exercise options.

### Clinical Practice

**Interventions Not Recommended**

The ONS Guidelines panel did not find evidence precluding any clinical interventions. Clinicians should not discourage exercise, and it is important to recommend that patients continue with any previous exercise regimen or incorporate new suggested exercises, with the caveat that a delay in resuming exercise postsurgery is recommended. The ONS Guidelines panel recommends strategies to reduce the risk of developing lymphedema and to manage lymphedema once diagnosed. These recommendations provide a foundation for patient education and early detection.

**Interventions Without Sufficient Evidence**

The guideline panel did not find sufficient evidence to support the use of compression garments for prevention of truncal, upper extremity, or head and neck lymphedema. Additional research is needed in this area.

### Implications for Nursing

Cancer-related secondary lymphedema is prevalent and impactful in patients with cancer. Nurses are well positioned to implement evidence-based interventions to minimize progression of lymphedema and to manage lymphedema once diagnosed. In addition, nurses can educate patients and caregivers about signs of lymphedema to aid in early detection. Based on the ONS Guidelines for cancer treatment–related lymphedema, recommendations can be implemented, supporting appropriate referrals (e.g., lymphedema specialist for education about massage technique).

### Conclusion

Cancer treatment–related secondary lymphedema is connected to numerous types of cancer and their associated treatments. Lymphedema can cause physical and psychosocial challenges. Although a patient may complete treatment for cancer, they remain at risk for lymphedema for life. This clinical summary provides evidence-based recommendations for prospective surveillance, risk reduction, and management. In addition, these recommendations provide a foundation to educate the patient about how to reduce the impact of lymphedema.

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**TABLE 1. (CONTINUED)**

**SUMMARY OF RECOMMENDATIONS: ONS GUIDELINES™ FOR CANCER TREATMENT–RELATED LYMPHEDEMA**

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<tr>
<td>Treatment (continued)</td>
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<tr>
<td>Recommendation 7: Among patients with cancer treatment–related secondary lymphedema, the ONS Guidelines panel suggests supervised water-based activities or yoga in addition to self-management rather than self-management alone.</td>
<td>Conditional</td>
<td>Very low</td>
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<tr>
<td>Remarks: Preference for water-based exercise or yoga or self-management may be driven by cost and accessibility.</td>
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CDT—complete decongestive therapy; MLD—manual lymphatic drainage; ONS—Oncology Nursing Society

LYMPHEDEMA

Development of the guideline on which this clinical summary was based was wholly funded by the Oncology Nursing Society, a nonprofit organization that represents oncology nurses. No honoraria were provided.

REFERENCES

IMPLICATIONS FOR PRACTICE
- Understand that patients remain at risk for secondary lymphedema for life and experience decreased quality of life and functional capacity. Once a patient is diagnosed, nonsurgical and conservative approaches should be considered before more invasive treatments.
- Advocate for prospective surveillance, which can reduce the risk of progression to later stages of secondary lymphedema. Educate patients and caregivers about lymphedema to aid in early detection and intervention.
- Encourage exercise, particularly in patients who are already exercising, for risk reduction of lymphedema.