GUIDELINES FOR SELF MANAGEMENT OF LYMPHOEDEMA

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You must have control of the authorship of your own destiny. The pen that writes your life story must be held in your own hand.

Irene C. Kassorla
Self Management in Lymphedema

1. Prevention and Risk Reduction
2. Secondary Lymphedema
3. Lymphatic Filariasis
Prevention and Risk Reduction

■ Who is at risk:
  - Every individual after lymph node dissection surgery and/or radiotherapy
  - Individuals post traumatic injury

■ When do we begin self management strategies
  - Pre-operatively for education and information
  - Interval surveillance post operatively
Prospective Surveillance Model

- Diagnosis
- Cancer Treatment
  - Pre-Operative Rehab: Assessment and Intervention
  - Early Rehab: During Disease Treatment
  - Ongoing Surveillance and Continued Interval Functional Assessment
- Cancer Survivorship
  - Referral to/Initiation of Rehabilitation Interventions

Adapted from Stout et al, Cancer, 2012
Pre-Operative Education

Promote Awareness of Lymphedema and Discuss Onset Symptoms and Management Approach

Assess Baseline Measures of Limb Size - Bilaterally

Develop a Follow Up Plan of Care

Knowledge is power, but sometimes it breeds fear

Provide information in context of their condition

Provide information in written form
Pre-Operative Education

Doing

- Flexibility Exercises
- Self MLD
- Breathing

Knowing

- Risk Reduction
- Symptom Identification
- Acting on Limb Changes

K I S T
Post Operative Follow up

Discuss Risk Based on What is Known

Review Information from Pre-Op

Teaching the Doing

Have a Plan for Follow Up
Post-Operative Education

Doing
- Flexibility Exercises
- Self MLD
- Scar Tissue Management

Knowing
- Risk Reduction
- Symptom Identification
- Acting on Limb Changes

K I Specific
Risk Reduction Guidance

Healthy Lifestyle:
A healthy diet and exercise are important for overall good health.

Skin Care:
Make sure that your skin is in good condition.

Medical Check-ups:
Find a certified lymphedema therapist (CLT).*

Infection Education:
Know the signs of infection and what to do if you suspect you have one.

TRY TO AVOID POSSIBLE TRIGGERS

- Injury or Trauma
- Limb Constriction
- Extreme Temperatures
- Prolonged Inactivity
Ongoing Surveillance and Monitoring

Repetition
Repetition
Repetition
Repetition
Repetition

Mastery
Secondary Lymphedema

If you want to make peace with your enemy, you have to work with your enemy. Then he becomes your partner.

Nelson Mandela

**Basic Self Care**
- Maintain Skin Integrity – moisturizing skin and improving nail care
- Remedial exercise programs
- Compression garment or other compression therapies

**Additional Components**
- Resistance exercise
- Pole walking
- Yoga
- Deep Breathing
- Self MLD
- Self Bandaging (condition dependent)

**Instruction in Self Care**
- Provided to patient and family member
- Range of sessions from 1 time 1 hour to 4 days of sessions
- Provide printed instructions
- Digital media support may be helpful

**Follow Up**
- Clinic follow ups at intervals between 2-12 weeks over 6 months.
Effectiveness of Self Care

<table>
<thead>
<tr>
<th>Self Care Strategy</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basic Self Care</td>
<td>No study assessed effect of self care alone on LE</td>
</tr>
<tr>
<td>Topical creams</td>
<td>No study assessed the effect of creams on LE</td>
</tr>
<tr>
<td>Home-based exercises*</td>
<td>Improvement in relative limb volume</td>
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<tr>
<td></td>
<td>Improved limb function (grip strength, muscle strength, ROM)</td>
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<tr>
<td></td>
<td>Improved self reported symptoms (heaviness, numbness, tingling)</td>
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<td></td>
<td>Improved QOL</td>
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<tr>
<td>Self MLD and Compression</td>
<td>Reduced limb volume</td>
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<td>Improved arm symptoms</td>
</tr>
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<td>Improved arm function</td>
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*All studies in Breast Cancer
Lymphatic Filariasis

The most powerful medicine in the world is knowledge.
Basic Self Care
- Limb hygiene – frequent washing and drying with soap and water
- Limb elevation
- ROM exercises
- Topical creams for lesions

Additional Components
- Compression garments*
- Self compression bandaging*

*Studies reported low usage levels and poor adherence

**Instruction in Self Care**
- Followed WHO Community-Based Home Care guidelines
- Provided to patient and family member
- Provide printed instructions

**Follow Up**
- Clinic follow ups at monthly intervals over longer durations (1-2 years ongoing)
# Effectiveness of Self Care

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| Basic Self Care          | • Reduction in episodes of infections (both frequency and duration of infections)  
                           | • Greatest improvements were among those with the most severe condition (Stage III)  
                           | • Improvements in limb volume were greater in less severe conditions (Stage I)*  
                           | • Significant improvements in QOL and self-reported disability                                                                         |
| Topical Creams           | • No differences noted between plain vs. medicated creams  
                           | • All cream users had reduced rate of infections over 12 months (similar findings with varied types of soaps)  
                           | • Segmental limb volume reductions were minimal                                                                                         |

*2 studies reported that a significant number of participants had reduced their stage by 1 level over 12 months.
Effectiveness of Self Care

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<td>Self MLD and Compression*</td>
<td>Significant reduction in limb volume</td>
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<td>Adherence was good with the majority of participants reporting compliance</td>
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<td>with recommended self techniques over 1 year</td>
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*Only one study*
Key Take Home Points

- A Prospective Surveillance Model enables early and ongoing engagement with patients at risk of developing secondary lymphedema related to cancer.

- Repeated interval assessment and reinforcement of techniques enable improved uptake and adherence.

- Cancer-related lymphedema self-care techniques that include home-based exercises, self-MLD and compression therapy combined with basic self care appear to have the strongest impact on improving limb volume, limb function and quality of life.

- Lymphatic filariasis and its related infections can be well managed with basic self-care techniques but limb volume is not substantially impacted. The use of self-MLD and compression therapy can aid in reducing limb volume but these techniques are not prevalent in LF management.
Unresolved questions...

- Exercise is impactful but is not taught nor commonly used in LF self-care trials.
- Basic care strategies have been codified in a guideline by the World Health Organization for LF but no efforts have been undertaken to extend this guideline to secondary lymphedema from other causes.
- Very few of the LF self-care studies investigated self-reported symptom changes or functional outcomes but these are prevalently reported in cancer-related lymphedema self-care studies.
- How do health care providers, in any setting, perceive and utilize self-care strategies. What is the optimal timing and frequency for engagement and education for self care?
“If I continue to define myself by what I can’t do, or what normal people do, I will destroy myself.”

Quote from LauraChamberlain.co.uk
Thank you