



# LISG

## Lymphedema Information Support Group

### Caring For A Patient With Lymphedema of the Head, Neck, Chest and Upper Back Post-Laryngectomy Complicated by Osteoradionecrosis

By Phyllis Tubbs-Gingerich - RN, BSN, LE, CLT-LANA, Lymphedema Therapist

I would like to share a case study about a man who had severe lymphedema of the head and neck. Although lymphedema manifests itself differently in each patient, there is always something we can learn from each individual case.

This patient's history included many years' smoking, and by late 1997, at the age of 50, he began having multiple complaints of pain in his neck and throat. Manifesting these symptoms and having a history of laryngeal carcinoma with radiation therapy of the neck, upper chest, and back, by early March 1998, following a direct laryngoscopy, the patient was diagnosed with a non-functional larynx and post-radiation complications. A total laryngectomy was performed in late March 1998, and a permanent tracheostomy was made. Because of severe radiation changes of the neck and upper chest, the skin, subcutaneous and muscle tissues were all hypovascular, woody, and necrotic. As a result, the neck wounds broke down post-surgically, leaving large open draining wounds and fistulas.

To facilitate wound closure and healing over the ensuing months, several surgical reconstruction procedures were performed. By late October 1999, all neck wounds were healed and the patient began vocal rehabilitation.

Throughout 18 months of surgical reconstruction, lymphedema became a serious problem. Since his neck was affected bilaterally, by early February 2000, his lymphedema began causing severe discomfort. After several attempts to reduce swelling by using conventional methods, the patient was referred for evaluation and treatment of lymphedema.

Preceding the patient's first visit on February 22, 2000, his chief complaints were: severe headaches, especially in the parietal and occipital head areas; discomfort around the eyes due to bulging of soft tissues; very reduced range of motion of the neck due to adhesions; inability to sleep; severe swelling of the face, cheeks, and chin; breakdown of the skin in radiated areas; severe coughing spells; and reduced ability to swallow solid foods.

Because of a permanent tracheostomy, the patient conversed by means of a Blom-Singer Valve.

Lymphedema was present throughout the head, neck - anterior and posterior, upper chest and back with severe fibrosis in the chin, lower cheeks, occipitus, and posterior neck. The patient's eyes were nearly closed due to lymphedema of the upper and lower eyelids. In addition, the facial skin was very red, irritated and congested and he became very concerned about large pimples appearing on his nose.

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All radiated skin was very dry and the surgical scars on the upper chest and neck were rigid and very sensitive to touch. These scars extended almost entirely from right to left axillae. It was apparent after reading all surgical reports and examining him, lymph was not passing anteriorly through normal channels.

Protocol for manual lymph drainage was designed to move lymph in the opposite direction: upward over the face, forehead, top of head, and down back of head, neck and back into posterior axillae and inguinals. After protocol for therapy was finalized, a detailed drawing outlining lymph movement served as the basic sketch for the fabrication of a specially designed compression headgear and a vest with directional flow.

At his second visit, the first "prototype" gear was fitted prior to therapy. Within 15 minutes there was visible reduction. Because these were newly designed directional flow compression garments, we had to be sure the patient was comfortable wearing both garments. These garments would not only be important for maintaining lymphedema reduction, but also they would serve to soften surgical scars and fibrosis, thus affecting a greater range of motion.

The patient was treated three times each week. He was also instructed in self manual lymph drainage, intensive skin care of all affected areas, application and care of his directional flow headgear and vest, and exercises to gradually increase range of motion of the neck. During clinical treatment strict therapy guidelines were followed while the patient devised ways at home to move lymph into areas he could not reach, e.g. using a small paint roller to move lymph down the back of his head and neck. Daily use of A&D Ointment completely softened and "flattened out" the surgical scars across the chest and there was evidence some lymph may have moved through these areas.

As therapy progressed, the patient was requested to write a daily log of events/progress/changes between therapy sessions. This reduced the amount of time he had to talk before therapy thus diminishing his coughing episodes.

With each coughing incidence, lymph backed up into his face and eyes, decreasing the effectiveness of MLD. The patient continued to state that with each therapy session, his headaches reduced in intensity but the problem of lymph collecting and thickening at the back of his neck seemed to always be a challenge. We tried to devise ways to meet this problem "one therapy at a time." "Swell spots" had been created for fibrotic areas such as the chin, lower cheeks, and back of neck. As fibrosis would build, sometimes overnight, these "swell spots" gave him the flexibility to place them inside his headgear in problem areas where he felt he needed more compression.

The patient's facial skin developed a "rosacea-like" appearance with extreme redness and breakouts. Each coughing spell triggered these symptoms and became a source of concern. Light creams and moisturizers were used to reduce facial congestion and relieve sensitivity and redness.

We continued to treat him two to three times each week for nine months with intensive MLD in areas most needed. His daily log informed us before each session what had occurred between sessions. This dictated our treatment plan for each future therapy session.

The past years have brought many changes in this patient's life. Throughout his treatment, we learned how daily physical changes, such as he experienced, could demoralize the spirit. He taught us that no matter the situation, "fighting back" can bring a certain higher quality of life.

Our therapy continued to be "one therapy at a time" to meet his changing needs.

## Dietary Corner

The Federal Trade Commission (FTC) has set in motion its "Red Flag" education campaign to help both the general public and the media recognize weight-loss product advertisements with misleading promises, using "too good to be true" claims. The FTC reports that ads making any of the following claims are almost surely bogus or misinforming:

1. The product causes weight loss of two pounds or more a week for a month or more without following a diet or exercise regimen
2. The product causes considerable weight loss, no matter the type or amount of food the buyer eats
3. The product causes permanent weight loss, regardless if it is no longer used
4. The product blocks the absorption of fat or calories to allow the buyer to lose a significant amount of weight

### Salsa Verde Recipe

#### Ingredients:

2-3 chili peppers of your choice such as poblano, jalapeno, serrano, etc. (or to taste)  
4-6 tomatillos (depending on size)  
1/2 bunch green onions  
1-2 cloves garlic, minced  
1/2 teaspoon coriander seeds, toasted and crushed  
Juice of 1 lime (to taste)  
1/2 bunch cilantro, finely chopped



### PREPARATION

1 - Preheat broiler. Wash and dry chili peppers. Remove husks from tomatillos, wash and pat dry. Place chili peppers and tomatillos on a baking sheet; broil 3 to 5 minutes each side until blackened. Remove from oven.

2 - Set hot tomatillos aside. Place the chili peppers in a bowl, cover with plastic wrap or an airtight lid, and allow to steam for 10 minutes. After 10 minutes, remove chili peppers. Using a sharp knife, remove stems, skins and seeds.

3 - Roughly chop tomatillos, chili peppers and green onions. Place in food processor or blender and add garlic and toasted coriander seeds. Pulse until uniform in texture, but not pureed. Stir in lime juice, cilantro, and salt, to taste.

4 - Serve with tortilla chips or with grilled fish or chicken.

# Healthy Feet

## How Diabetes Affects Your Feet

**Poor Blood Flow:** Minor foot problems like: bunions, blisters, cracked skin, corns and calluses are slow to heal or don't heal properly due to poor blood flow. Open sore and/or infections can result.

**Nerve Damage (Diabetic Neuropathy):** Damaged nerves result in numbness and a reduced ability to feel pain, increasing the potential for undetected foot problems to become infected.

**Keys to Preventing Diabetic Foot Ulcers:** Proper foot care, protecting your feet from injury, avoiding the use of alcohol or tobacco and employing methods to improve blood circulation.

### Proper Foot Care Includes:

Look at and touch your feet everyday.

Keep feet clean, dry, and warm.

Cut or file toenails with the shape of the toe, smoothing all edges.

Wear only well-fitted, soft leather, or fabric shoes.

Check shoes daily for cracks, pebbles, or other things that might damage your feet.

Wear well-fitting socks, without a thick toe seam, made of material that wicks moisture away from skin.

Wear a clear pair of socks every day.

Get custom orthotics that are designed from the topography of your feet,

Avoid sitting with legs crossed,

Avoid any position that compromises circulation in the legs, e.g. sitting too long in a 90 degree angle for ankles, knees, and hips.

Using a light water-base lotion, daily massage the feet lightly in an upward motion (toes toward knee).

Exercise – swimming, cycling, walking or an elliptical machine are best. Except when swimming, wear well-fitted shoes and custom-made orthotics while exercising.

Natural remedies such as Ginkgo biloba may be helpful. Talk this over with your MD prior to use.

Keep your blood sugar and diet under control.

Control or minimize swelling in your feet and legs – use of gradient compression stockings.



# Healthy Feet

## Medical Footwear



Women's hiker with a steel shank for maximum support



Great Euro styling with adjustable closures and contoured foot bed



Multi-functional pumps with non-slip leather soles for a professional setting



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### Why Feet Love Drew Shoes

Fit like a glove  
Do not hurt  
Plenty of room for toes  
Solidly constructed  
Attractive and practical



# Unpredictable Lymphedema

By Phyllis Tubbs-Gingerich, RN, BSN, CLT-Lymphedema Specialist, LANA/Vodder

*Be  
Prepared*

**Lymphedema** is very unpredictable and when environmental conditions change, lymphedema changes too. Knowing how to care for yourself and having the supplies/equipment necessary for self care enables you to lead an independent, self efficient life wherever you go and/or whatever you do.



## CONDITIONS THAT SEEM TO COMPLICATE OR WORSEN LYPHHEDEMA

Radiation  
 Extreme heat  
 Chemotherapy  
 Reconstructive surgery  
 Infections  
 Any invasive treatment/surgery  
 Air travel  
 Blood pressure on affected arm  
 Increased altitudes - above 4,000 ft.  
 Breast Implant preparation  
 Repeated aspirations of body fluids  
 Injections on the affected arm or leg  
 Body massage of the affected quadrant  
 Liposuction of the affected area  
 Any surgery in the affected quadrant

## Lymphedema Self-Care Manual



Phyllis Tubbs-Gingerich  
RN, BSN, LE, CLT - Lymphedema Specialist

The need for a detailed resource guide for lymphedema self-care prompted the publication of this "easy-to-carry" manual.

We hope our 1st edition will answer questions you have about lymphedema and guide you through a better understanding of self care.

This book is not intended to be a medical manual or to replace your physician's care and advice, but rather as a guide to aid in self care and maintenance of lymphedema, skin and wound care. It is the culmination of 30 years' experience in the field of cancer, lymphedema, skin and wound care.

Self care suggestions in this book are the direct result of patient's subjective comments, which have prompted us to research better methods of treatment.

Over the years, these formulas have been used in treating our patients and have not only become part of our clinic's protocol for therapy but have proven to be a vital tool for education of patients in self care and maintenance. This constant exchange of information between patient and lymphedema specialist continues to be the basis for individualized patient care at our clinic.

*The best way to treat lymphedema is to:*

- *Get as much information as possible about lymphedema.*
- *Seek proper care and instructions from a bona fide lymphedema specialist.*
- *Secure materials and supplies necessary to properly maintain lymphedema.*

Order your copy of the ***Lymphedema Self-Care Manual***  
**\$39.68**

( \$32.00+ \$2.68 Tax + \$5.00 Shipping )  
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**Phyllis Tubbs-Gingerich, RN, BSN, LE,  
CLT,  
Certified Medical Wig Fitter for Alopecia**

**By appointment only.  
Contact Phyllis at 408-782-1028  
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[phyllis@gingerkcenter.com](mailto:phyllis@gingerkcenter.com)  
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## *3 Things in Life that:*

**Once gone, never come back -**

Time, Words, Opportunity

---

**Destroys a person -**

Anger, Pride, Lack of forgiveness

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**You should never lose -**

Hope, Peace, Honesty -

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**Are most valuable -**

Love, Family & Friends, Kindness

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**Are never certain -**

Fortune, Success, Dreams

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**Make a person -**

Commitment, Sincerity, Hardwork





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LISG is a non-profit organization and we depend upon your support.

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- Information regarding current treatment for lymphedema
- Other helpful information

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We appreciate your support.

Sincerely,

Phyllis Tubbs-Gingerich  
RN, Founder LISG

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