

# LYMPHEDEMA

A LESS KNOWN  
YET  
PREVALENT  
AND  
DEBILITATING DISEASE



This book is brought to you by  
India Lymphedema Foundation.

“Life should be full of fragrances. Life should have the power to fight through the clouds and see the brightness of the world”

At India Lymphedema Foundation, our mission is to orchestrate holistic therapy for lymphedema patients and empower them to manage the symptoms for a better quality of life.

Our goal is to raise awareness, institute education and provide outreach through appropriate lymphedema therapies.

The intent of this book is to provide you with a quick reference to understand and manage lymphedema.

This book is dedicated to my parents, Mr. Markand Dave, Mrs. Rita Dave, Mr. Vasudev Pathak, Late Mrs. Bharati Pathak as well as all lymphedema patients that strive to improve their quality of life.

Special thanks for Dr. Sanjay Dudhat, Dr. Gurusamy, Dr. Zoeb Rangwala, Dr. Kamran Khan, Dr. Manish Motwani, Dr. Anil Heroor, Dr. Purvi Gada, Michele Coxon (CLT, CMT), Mr. Jaydeep Pathak, Mr. Ramon Abrol, Mrs. Baku Abrol, Mr. Arun Wadhwa, Mrs. Manjusha Vagal (OT), Late Dr. J.T. Vyas, and Rotarians for their encouragement in advancing our mission.

NOTE: Always refer to your physician for complete medical advice and treatment plans. This book is not intended to substitute for medical care. This book is not intended for commercial sale.



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## Lymphedema in Simple Words

Lymphedema is a chronic disease that results in a build-up of lymph fluid (swelling). It occurs when the lymphatic system is either faulty or damaged. There are many causes, but the most common are cancer treatments involving removal of the lymph nodes or lymph vessels or damage during the surgical procedure and treatment such as radiation. Filariasis related lymphedema is also seen in certain geographies.

When lymph nodes and lymph vessels are removed or affected, the lymphatic fluid may not drain effectively. This causes build-up of fluid under the skin and thus the swelling. Lymphedema most commonly occurs in the limbs (arms and/or legs). Occasionally, it occurs in other parts of the body such as the head, neck or trunk.

Lymphedema can progress beyond any cure if not managed through appropriate treatment.



## Causes for Lymphedema

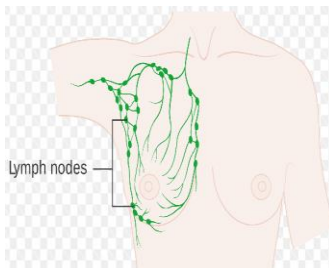
- Primary lymphedema is caused by the abnormal development of the lymph system. Symptoms may occur at birth or later in life.

Although rarely seen in children and adolescents, it is believed to primarily occur in girls near menarche. The influences of estrogen and inflammation are thought to be important etiologic factors in primary lymphedema.

- Secondary lymphedema is caused by damage to the lymphatic system or blockage of the lymph vessels.

Common causes of Secondary Lymphedema:

Damage or blockage of the lymphatic system as a result of factors such as infection, injury or trauma, cancer, surgical removal of lymph nodes, radiation to the affected area, or scar tissue from radiation therapy or surgery. Obesity makes lymphedema management more difficult for patients.



## Stages of Lymphedema

**Stage I:** Stage I lymphedema presents as an initial swelling of the limb that is temporarily reduced by elevation of the limb. However, this stage of lymphedema often goes unrecognized. It can be mistaken as a temporary swelling that can be caused by other factors. Thus, early intervention which makes it reversible, is often not sought by the patient.

**Stage II:** Stage II lymphedema creates a chronic condition known as Fibrosis in which there is a thickening of the connective tissue. This is referred to as spontaneously irreversible stage. If the condition is not addressed aggressively at this stage, the tissue continues to harden and thicken; fungal infections can arise causing greater congesting and the condition worsens.

**Stage III:** The condition can progress to stage III called as lymphostatic elephantiasis where the swelling is extreme, the skin is hardened and shows wart-like growth. Sometimes large bulges appear due to fluid accumulation. The risk of wound inflammation increases causing the skin to become vulnerable to deep, poorly healing wounds.

## Lymphedema Diagnosis Methods

### **You may have lymphedema if you experience:**

- Swelling that is not resolving
- Swelling that is getting worse
- Swelling that feels warm with a rash
- Swelling with discomfort and pain
- Swelling with fever and chills
- Swelling with decreased flexibility in the joints
- Difficulty fitting into clothing or jewelry
- Weakness, tightness, pain or heaviness
- Dull ache in the affected limb
- Pitting of your skin

### **Consult your medical professional for diagnosis.**

### **Lymphedema diagnosis methods may include:**

- Lymphoscintigraphy
- Near Infrared Florescence imaging
- Ultrasound
- MRI scan
- Doppler Ultrasound
- Bioimpedence spectroscopy
- Perometry
- Volumeters
- Circumferential Tape measurement
- Genetics testing

NOTE: Diagnosis and lymphedema assessment must be performed by trained medical professional.

# Lymphedema Treatment Options

Lymphedema treatment not only reduces the swelling, but it also reduces the incidence of infection, cellulitis, emotional burden of altered body image, and dependence on others. Treatment includes initial phase and maintenance phase.

The initial treatment phase options include:

## **Complete Decongestive Therapy (CDT)**

Recommended activities include for CDT include:

- a. Manual Lymphatic Drainage (MLD)
- b. Compression Therapy
- c. Exercise  
(Recommended CDT protocols can help stimulate the lymphatic system and get the fluid moving)
- d. Elevation
- e. Diaphragmatic breathing
- f. Meticulous skin and nail care

## **Physiotherapy**

## **Pneumatic Compression**

(Avoid using lymphatic compression pumps, as substitute for MLD/CDT)

## **Surgery**

## **Drug therapy**

(Medication such as diuretics may be used however long term use may cause fibrosis)

## **Lymphedema (Elastic) Taping**



## Ongoing Management (maintenance) of Lymphedema

- a. Manual Lymphatic Drainage massage**
- b. Compression garments**
- c. Routine exercises**  
(as recommended by the therapist and elevation of the affected extremity)
- d. Self manual lymphatic drainage massage** (as taught by the therapist)
- e. Skin-care precautions**
  - Use sunscreen and insect repellants to minimize dangerous skin exposure and bug bites
  - Use electric razors to prevent razor cuts
  - Wear Protective clothing (gloves for hands and sturdy, well-fitted footwear for feet) during activities where there is a risk of cuts, insect bites or other minor injuries (BE AWARE that infections can result from insect bites, manicures, pedicures, skin punctures, cuts, pet scratches or other minor breaks in the skin).
  - Use neutral-pH soap
  - Use lotions for moisturizing  
(vegetable based products are recommended rather than mineral oil or petroleum based products)

**Good nutrition and plenty of water is important. Diet should include lot of fresh fruits and vegetables.**

## Manual Lymphatic Drainage (MLD)

MLD is a light and gentle manual modality performed by trained and certified therapist. MLD stimulates the activity of lymph vessels and enables the flow of lymph fluid. It follows alternate lymph drainage pathway following appropriate protocol.

MLD should be performed at a frequency established by therapist.

**NOTE:** MLD should follow compression bandaging or wear compression garments.

To avoid accumulation of the lymph fluid after MLD, compression on the affected extremity/anatomy is vital. This will lead to sustained benefits from MLD.



Common contraindications that may require MLD to be suspended or modified include:

- Acute infection/ inflammation/ allergic reaction
- Untreated malignancy/metastatic cancer
- Untreated thrombosis
- Cardiac insufficiency, cardiac decompensation
- Thyroid disorder
- Pregnancy
- Nevus
- Low blood pressure
- Menstruation (early in the cycle)
- Co-morbid conditions like respiratory distress

## Nutrition and Lymphedema

### Good nutrition is important.

Eat a healthy and balanced diet consisting of whole grains, fruits and vegetables, low-fat dairy and protein foods such as beans/nuts and lean meats. This will help maintain a healthy body weight and will ensure appropriate intake of vitamins and minerals.

Overweight and obesity are associated with increased lymphedema. Thus, maintain a healthy weight.

- Portion control is important for achieving and maintaining a healthy weight.
- Aim for low-calorie frequent meals throughout the day which will prevent from over-eating at a single meal.
- Avoid high calorie prepared and convenience foods and “empty calories.”

Although not scientifically substantiated, salt is thought to impact lymphedema. Limiting salt/sodium intake (e.g. 1500mg/day) may be recommended by your medical professional.

Fluid intake is especially important. It helps to flush waste products from the body following lymphedema treatments. Consume 2-3 liters of water daily.

## Treatment Providers

Complete Decongestive Therapy should be provided by Medical Professionals who are trained in:

- a. CDT practices through reliable institutions
- b. Specialized manual lymphatic drainage massage
- c. Compression bandaging

Medical professionals such as oncologists, vascular surgeons, plastic surgeons should be consulted.

Lymphedema therapists should have a degree in physiotherapy, occupational therapy, massage therapy or similar medical-related field.

## What questions should you ask your therapist?

Ask about initial treatment and ongoing management:

- a. Assessment results and treatment plan
- b. Contraindications, advantages and disadvantages of treatment methods
- c. Suspected conditions that need physician involvement
- d. Life-style changes including exercises, self-care, nutrition, activities that should be avoided
- e. Long-term management plans

NOTE: Be sure to provide all your medical history and information of current health condition to the therapist.

## Risk Concerns

### **If you have lymphedema, ask your Physician or Therapist regarding:**

- Blood draws or blood pressure cuffs on the affected limb
- Breast prostheses
- Hot baths, hot showers, hot tubs, saunas
- Exposure to extreme hot or cold temperatures
- Direct deep-tissue massage on impacted areas
- Food restrictions
- Air travel and compression garments
- Prescription for antibiotics (oral and/or topical)

### **Avoid:**

- Tight jewelry or clothing especially undergarments which can be constrictive
- Heavy or repetitive lifting, pushing, or pulling
- Exercises that cause pain and fatigue

NOTE: If you observe symptoms of infection (e.g. fever, rash, redness, chills or hot skin) or other changes that may be related to lymphedema, consult your therapist or physician promptly.



## Sources for Additional Information

Understand what is lymphedema and treatment options from physician or therapist.

Additional recommended resources include the following:

- [www.lymphnet.org](http://www.lymphnet.org) (National Lymphedema Network)
- [www.lymphnotes.com](http://www.lymphnotes.com)
- [www.lighthouse.lymphedema.org](http://www.lighthouse.lymphedema.org)
- [www.stepup-speakout.org](http://www.stepup-speakout.org)
- [www.cancer.gov/cancertopics/pdq/supportivecare/lymphedema/patient](http://www.cancer.gov/cancertopics/pdq/supportivecare/lymphedema/patient)
- [www.ilf.org](http://www.ilf.org)

Lymphedema information presented by: Ira Dave, M.S.

Information on Nutrition provided by: Jayna Dave, Ph.D. Baylor College of Medicine

Endorsed by: Dr. Purvi Gada, MD – Minnesota Oncology; and Michele Coxon, CMT and CLT

[www.ilf.org.in](http://www.ilf.org.in)

[ilf.awareness@gmail.com](mailto:ilf.awareness@gmail.com)

Lymphedema is a feared clinical sequelae post cancer treatment and significantly affects quality of life. Patients experience recurrent infection, pain and excessive fatigue, depression, difficulty with movement, reduced activity, dependence on others, self-consciousness about appearance and more.

Several types of cancers such as breast, cervical, endometrial, vulvar, prostate, penile cancers, soft tissue sarcoma are associated with occurrence of lymphedema. Bacterial lymphangitis as well as peripheral artery disease and varicose vein surgery are known contributing factors.

Standardized diagnosis and treatment options are limited.

“The little hand guide book is an excellent, comprehensive resource for lymphedema in a nut shell. It touches all the important topics related to lymphedema and underscores the importance of early diagnosis and intervention. This is a handy book for quick reference for patients with or at risk for lymphedema. Reading it strikes the need for increasing awareness and treatment accessibility for this debilitating disease.”

- Dr. Purvi Gada, MD – Minnesota Oncology

"This book on lymphedema does an excellent job of providing a wealth of information with clarity and simplicity for anyone suffering this disease. It should be kept close at hand as a reference guide book and manual on self-care and management of lymphedema. Good for therapists as well as patients."

- Michele Coxon (CMT, CLT)

Join us at India Lymphedema Foundation to raise awareness, treatment and support options for patients and their families.



[www.ilf.org.in](http://www.ilf.org.in)