NATIONAL LYMPHEDEMA NETWORK

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The NLN Mission Statement

The mission of the NLN is to create awareness of lymphedema through education and to promote and support the availability of quality medical treatment for all individuals at risk for or affected by lymphedema.

The NLN is dedicated to:

- *promoting research into the causes, prevention and treatment of lymphedema;*
- *securing adequate insurance coverage for medically necessary, safe and effective treatment;*
- *expanding the number and geographical distribution of lymphedema treatment facilities and certified therapists.*

To achieve these goals, the NLN disseminates information about lymphedema to health care professionals so they can appropriately counsel their patients on its avoidance, and prescribe safe, effective treatment for those affected by this condition. The NLN also provides this information to the general public.

When It Isn't Lymphedema

By Paula J.B. Stewart, MS, MD

Those who care for lymphedema (LE) patients are well aware of the typical etiologies of Secondary Lymphedema, the most common form of LE in developed countries. These etiologies include surgery, radiation, trauma, infection and filariasis, and result in the accumulation of high protein edema in the soft tissues. Primary Lymphedema accounts for only about 10% of LE cases and can occur at the time of birth, during puberty, or later in life. In these cases, the LE is almost always associated with an abnormality in the lymphatic vessels. Primary Lymphedema also can be associated with congenital syndromes such as Yellow Nail, Hennekem's, Noonan's or Turner's syndromes.

There are many conditions that can cause swelling that are not LE. It is important for those treating LE to understand the various causes and treatment approaches to the different diagnoses. In some cases, failing to recognize that the swelling is not LE can lead to harm of the patient. The most critical diagnoses will be discussed first. Next, the mixed edemas will be addressed and then those edemas which are not amenable to typical lymphatic treatment.

The following conditions can be called the "Dangerous Look-Alikes" and include:

1. Malignant Lymphedema
2. Deep Venous Thrombosis
3. Congestive Heart Failure
4. Cellulitis

Each can be associated with edema and Manual Lymphatic Drainage (MLD) is contraindicated in each case.

Malignant Lymphedema results from tumor obstructing or compressing lymphatic vessels or lymph nodes. This usually occurs in the axillae or groin and often presents as a rapidly progressive, painful, proximal edema. There is often a burning or shooting pain associated which is indicative of nerve involvement. In this circumstance, it is important for the therapist to have excellent communication with the treating physicians, especially the oncologist. Diagnosis is made with a CAT scan or MRI. There is a theoretical concern that MLD and compression wraps or garments may spread the cancer, although there has been no research demonstrating that compression spreads cancer. If the patient is terminal and the goals of treatment are palliation, then wrapping or compression should be offered if it results in increased comfort. If the patient is undergoing further potentially curative interventions, no MLD should be performed and, at most, a light compressive sleeve such as Kati, Tubigrip or Tensigrip can be offered. The administration of radiation or chemo usually results in shrinkage of the tumor and rapid resolution of the painful edema.

Deep Venous Thrombosis is the formation of a clot in the deep veins of a limb or pelvic veins. The first indication of thrombosis is often swelling accompanied by pain in the affected limb. Diagnosis can be made by a Doppler study or spiral CT and, if positive, anticoagulation therapy is usually initiated. There is controversy in the field regarding the initiation of therapy for associated edema. The most conservative practitioners recommend no MLD or compression for six months. The trend in recent times has been to initiate compression without MLD two weeks after the patient has achieved therapeutic

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anticoagulation. MLD usually can be started six weeks after therapeutic anticoagulation. The concern, of course, is that the compression or manipulation of the limb could result in a potentially fatal pulmonary thrombo-embolism.

Congestive Heart Failure (CHF) often manifests as swelling in the legs. The therapist must be vigilant for this diagnosis in any patient with heart disease. A simple blood test for Brain Naturoritic Peptide (BNP) can diagnose the condition. The edema is low protein and rarely results in fibrosis of the affected limb. Initiating treatment in a patient with CHF can result in severe exacerbation of the CHF and potentially life-threatening outcomes. The usual treatment approach is diuresis and elevation of the legs. In extraordinary cases, when the patient is in a hospital setting with cardiac monitoring available and a cardiologist, the legs may be wrapped in a stepwise fashion, i.e., starting with one half leg, then a second half leg, then one leg toe to groin, then a second leg toe to groin, slowly progressed over several days. With close medical monitoring, the patient's CHF can be treated more rapidly.

Cellulitis often occurs in conjunction with LE. It can occur when LE is not present and cause associated swelling. It is caused by a Streptococcocal infection of the cutaneous and subcutaneous tissues. Acute Celiulitis is usually treated with a 10-day to 2-week course of antibiotics. Treatment when LE is present is controversial. The most conservative lymphologists will suspend wraps and MLD for up to six weeks after diagnosis and treatment. The concern is that systemic infection may occur with LE treatment. Other lymphologists are initiating compression wraps one day to one week after antibiotics have been started or when the erythema associated with the cellulitis has started to resolve.

Safely treating LE patients requires awareness of these diagnoses and vigilance in the management of these patients. If a "Dangerous Look-Alike" is suspected, close communication with the attending physician is critical so that a safe and effective treatment plan can be implemented.

Other look-alikes in LE include the mixed edemas. These include phlebo-lymphedema, lipo-lymphedema, and phlebo-lipo-lymphedema. All of these and the low-protein edemas such as those associated with renal failure, CHF, or hypoalbuminemia (anasarca) can result in a Secondary Lymphedema due to dynamic insufficiency in which the lymph flow exceeds the transport capacity of the lymphatic system. Most of the time, these edemas respond well to standard LE treatment in conjunction with mild diuresis and some of the precautions outlined above.

The final group of edemas to be discussed are those that are not LE and do not respond well to LE treatment techniques. Myxedema is the accumulation of a mucinous deposit in the subcutaneous tissues resulting from thyroid disease. The skin is often bronze colored and has a doughy feel. Treatment is best achieved by correcting the thyroid abnormality.

Idiopathic cyclic edema occurs in women and is related to hormonal shifts throughout the menstrual cycle. Some women have a sensitivity to estrogen, which causes extreme capillary permeability and, subsequently, large shifts of fluid into the interstitium with peaks in estrogen. Some women may experience painful edema and weight gain of 10-20 pounds during the month. The condition is best treated with low-dose birth control pills and mild diuresis with the fluid accumulation. Light compression may be helpful during the acute phase of the edema.

Chronic regional pain syndrome often initially presents with shiny, painful skin and edema resulting from a nerve injury or some other minor injury. There is significant autonomic dysfunction manifest as vasoactive changes in the skin. Pain is the defining feature of the condition and the patient will not tolerate massage or wraps to the limb. The treatment efforts should be focused on reduction of pain and prevention of atrophy and contracture.

Livedo reticularis is cold sensitivity that typically develops on the lower legs of young women. These patients will present with bluish, thickened skin and edema of the legs. The feet are usually spared. The condition is seasonal, occurring in the winter and resolving in the warmer months. Preventing exposure to cold and light compression are the best treatment approaches.

Artificial edema is self-inflicted edema, which results from application of a tourniquet or repeated trauma to the limb. This is rarely seen in the U.S., but is fairly common in those European countries where LE is a diagnosis that is compensated with disability payments. In the short term, the edema can be treated with usual LE techniques; however, ultimately, the self-injury must be halted to cure the condition.

In conclusion, not all edema is lymphedema. Healthcare professionals must be aware of the alternative diagnoses to safely and appropriately treat the LE patient. At best, treating the wrong diagnosis with lymphedema management techniques may prove ineffective; at worse, it may harm the patient. ❑

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