



LYMPHEDEMA

DIAGNOSIS AND TREATMENT COST SAVING ACT

Pending reintroduction in the 113th Congress
REPRESENTATIVE DAVE REICHERT (WA-8)

ENDORSED BY:

The American Cancer Society
Komen Advocacy Alliance
LiveSTRONG
Oncology Nursing Society
The American Physical Therapy Association
The American Occupational Therapy Association
The National Lymphedema Network
and many other groups

WHAT IS LYMPHEDEMA

Lymphedema is an incurable but treatable medical condition caused by injury, trauma or congenital defects in the lymphatic system. When the impairment becomes so great that the lymphatic fluid exceeds the lymphatic transport capacity, swelling results as an abnormal amount of protein-rich fluid collects in the tissues of the affected area.

Two types of lymphedema exist: primary and secondary. Primary lymphedema can be present at birth (congenital), develop at the onset of puberty (praecox), or in adulthood (tarda). Secondary lymphedema is acquired most often after the removal of lymph nodes for cancer surgery, radiation damage or other injury, and is sometimes seen as a secondary condition to other disabilities.

Lymphedema is classified in three stages:

Stage 1: When lymphedema is diagnosed in Stage 1, and consistent treatment is instigated, the disease can be reversed and/or prevented from progressing. There will be little or no visible swelling and patients can expect to live a long, healthy and virtually normal life with few to no complications.

Stage 2: Once progressed to Stage 2, consistent treatment can improve the swollen tissue and soften the fibrosis (hardening and scarring of the tissue), and progression of the disease can be halted. Patients can expect to have more frequent medical and social complications, such as recurring infection, decreased joint range of motion, body image dysfunction, decreased performance of activities of daily living, and certainly varying degrees of discomfort.

Stage 3: By Stage 3 the swollen limb(s) is/are very large, the tissue is hard (fibrotic) and unresponsive, and the damage is now irreversible. Potentially serious chronic pain and recurring difficult to treat complications which can be life threatening are to be expected. Patients with Stage 3 lymphedema are often fully disabled by the disease.

Examples of Stage 3 are pictured below:



How Is LYMPHEDEMA TREATED

The standard of lymphedema care is a protocol called Complete Decongestive Therapy, consisting of manual lymph drainage, compression therapy, exercises and skin care. It is administered in two phases; a clinical phase and a home care phase, elements of which are prescribed by the patient's physician and qualified therapist.

Initial treatment by a qualified lymphedema therapist consists of 2-6 weeks of frequent MLD sessions and compression bandaging, specialized decongestion exercises, and instruction in self-care for the second phase of treatment. After the initial swelling is reduced to a minimum by the professional therapist, the patient is measured for a compression garment(s) and continues self-treatment at home with simplified self-lymph draining, self bandaging, exercises while under compression, wearing of compression garments and meticulous skin care.

The goal is to transfer responsibility for ongoing treatment to the patient, thereby unburdening the healthcare system. The provision of the materials necessary for self-care remains the responsibility of the insurance healthcare system(s), else the patient cannot be adherent.

Patient photos of before and after treatment:



COMPLICATIONS OF LYMPHEDEMA

When lymphedema remains untreated, protein-rich fluid continues to accumulate, leading to increased swelling and a hardening or fibrosis of the tissue. In this state, the swollen limb(s) becomes a perfect culture medium for bacteria and subsequent recurrent infections (cellulitis and lymphangitis).

Moreover, untreated lymphedema can lead into a decrease or loss of functioning of the limb(s), skin breakdown, chronic infections and, sometimes, irreversible complications. In the most severe cases, untreated lymphedema can develop into a rare form of lymphatic cancer called Lymphangiosarcoma (most often in secondary lymphedema).

Since lymphedema is disfiguring, causes difficulties in daily living and can lead to lifestyle becoming severely limited, it frequently results in psychological distress. Lymphedema is a chronic and potentially debilitating condition with no currently known cure, but effective management of the disease can halt progression and reduce, and in many cases even prevent, complications.

Typical complications for those with untreated or under-treated lymphedema:



WHY THIS LEGISLATION IS NEEDED

Lymphedema affects an estimated 1.5 to 3 million Medicare beneficiaries who currently receive sub-standard treatment from Medicare according to the current medical standard of care. Untreated, or under-treated, lymphedema is progressive and leads to infection, disfigurement, disability and in some cases even death. Thus prognosis for the patient is far worse and treatment more costly when the disease is not identified and treated in the earlier stages.

Medicare does not currently cover the compression garments and bandages used daily in lymphedema treatment. While Medicare does cover and pay for statutorily limited therapy and sequential compression pumps, many patients suffer from recurrent infections, progressive degradation in their condition and eventual disability because they cannot afford the compression bandages and garments required for their everyday self-care.







States have already recognized that coverage for successful early treatment is essential and cost saving, and are beginning to require that private and state plans provide this coverage. A lymphedema treatment mandate went into effect in North Carolina on January 1, 2010, one has been in effect in Virginia since 2004, and several other states have similar legislation pending.

WHAT THIS LEGISLATION WOULD DO

The Lymphedema Diagnosis and Treatment Cost Saving Act will improve coverage for the diagnosis and treatment of lymphedema. This is a preventative treatment bill that will reduce health care costs while improving patient care and quality of life.

Medicare alone is spending billions of dollars every year treating largely preventable lymphedema-related cellulitis infections and other complications. Although this bill relates specifically to a change in Medicare law, it would almost certainly result in all private insurance policies following suit, thus improving the quality of care for all 5 millions Americans with lymphedema.

Specific goals of the bill are:

-  Comprehensive treatment coverage, according to current medical treatment standards, for individuals with and at risk for lymphedema;
-  The ability to add new treatment modalities to coverage as they become available and are approved;
-  Preoperative measurements for cancer patients to aid in early detection and diagnosis;
-  To provide for lymphedema patient education in the procedures for self-treatment so as to transfer the treatment from the clinical to the home setting;
-  To enable patient self-treatment plan adherence by providing necessary medical supplies for use at home, as prescribed for each patient (compression garments, compression bandages, other compression devices, pneumatic compression pumps, etc);
-  Reduction in total healthcare costs through avoidance of periodic infections, pain and disabilities resulting from this medical condition.



Endorsements for The Lymphedema Diagnosis and Treatment Cost Saving Act

CANCER & OTHER ORGANIZATIONS:

American Cancer Society - Komen Advocacy Alliance - Oncology Nursing Society
American Physical Therapy Association - American Occupational Therapy Association
Colon Cancer Alliance - LiveSTRONG - Sarcoma Foundation of American
Breast Cancer Action - Breast Cancer Network of Strength - Living Beyond Breast Cancer
Board of Certification/Accreditation (orthotists, prosthetists, pedorthists, orthotic & mastectomy fitters)
Society for Oncology Massage - American Association of Homes and Services for the Aging

LYMPHEDEMA ORGANIZATIONS:

National Lymphedema Network - Lymphatic Research Foundation
Lymphology Association of North America - Lighthouse Lymphedema Network
Lymphedema Awareness Foundation - Elymphnotes - Lymph Notes
Lymphedema Community - Lymphland - Lymphedema People
Step Up-Speak Out - The Annie Appleseed Project
American Lymphedema Framework Project

DOCTORS & TREATMENT CENTERS:

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David Finegold, MD & Robert Ferrell, PhD (Univ. of Pittsburgh Lymphedema Study)
Gil Yosipovitch, MD (Wake Forest University Health Sciences)
NC Comprehensive Cancer Program - Carolinas Rehabilitation
James Cancer Hospital - Northwest Lymphedema Center - Wyatt Rehabilitation
Siskin Hospital and Rehabilitation Center - Rivertown Lymphedema Clinic
Vascular Anomalies Center at Children's Hospital Boston - Highlands Oncology Group
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LYMPHEDEMA INDUSTRY:

Academy of Lymphatic Studies - Norton School of Lymphatic Therapy
Klose Training and Consulting - The Chickly Health Institute - The Vodder School
BSN Medical/Jobst - BiaCare - Farrow Medical Innovations - Impedimed
JoViPak Corporation - Juzo - Lohmann & Rauscher - LymphedIVAs
mediUSA - My Sassy Sleeve - Solaris - Torbot Group/Jobskin Division
Alala - Ames Walker International - Brown Medical Industries - Sigvaris
Close to You - In The Pink - SunMED Medical - Lymphedema Products
Essentially Women - Heart Strings Boutique - Orthokinect - Prosthetics Laboratory

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