In Support of HF 56: Coverage of Lymphedema Treatment by the Legislature of the State of Minnesota

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Nancy A Hutchison, MD Cancer Rehabilitation and Lymphedema Courage Kenny Rehabilitation Institute of AllinaHealth

MY CREDENTIALS

I specialize in the treatment of lymphedema. I have worked in this field for over 20 years, solely in the care of cancer and lymphedema patients since 2000. I served as the Chair of the Medical Advisory Committee of the National Lymphedema Network from 2011 to 2013. I am currently on the Board of Directors of the Lymphology Association of North America, which sets the standards of treatment and training for lymphedema therapists. I am the author of the Chapter on *Cancer-Related Lymphedema* for the 2nd Edition (2019) of the Textbook: Cancer Rehabilitation Principles and Practice, Editor: Stubblefield. My CV and Biosketch are attached.

LYMPHEDEMA IS LYMPHATIC ORGAN FAILURE

Lymphedema is a serious disease that occurs from damage to an internal body organ, the lymphatic system. The lymphatic system consists of lymph nodes, lymphatic vessels and other lymphoid tissues such as the spleen and thymus. The lymph nodes contain white blood cells (lymphocytes) that regulate immunity from bacterial invaders in the tissues and surveillance for cancer. When an individual has an injury to the lymphatic system or has abnormal development of the lymphatic system, the disease is known as lymphedema because the most obvious feature we see is swelling. But lymphedema is not like any other type of swelling. Lymphedema is LYMPHATIC ORGAN FAILURE, not just swelling. The lymphatic organ failure leads to build-up of stagnant lymph that progresses to both solid and liquid components that progress to deformation of body parts, pain, thickened skin, non-healing wounds, susceptibility to serious infections known as cellulitis, impaired mobility, reduced strength and limited range of motion of the affected part. These complications are preventable with the treatment called Complete Decongestive Therapy (CDT) including correct medical compression garments and devices. If improperly or inadequately treated lymphedema will progress, lead to expensive hospitalizations and become disabling.

LYMPHEDEMA: BOTH IMMUNE AND FLUID DYSREGULATION

Since the function of lymphatic system is *cell-mediated immunity* and *fluid regulation*, lymphatic failure (lymphedema) is both an immune system defect and a fluid regulation defect. Cell-mediated immunity is the immunity in our tissues, regulated through the lymph nodes and vessels (as opposed to humoral immunity, the type that is carried in the blood circulation and for which we get vaccines). Cell-mediated immunity requires a functioning lymphatic system for surveillance and elimination of foreign invaders in the tissues. Lymphatic vessels are formed from thousands of tiny "heart-like" chambers, called lymphangions. These lymphangions have their own pacemaker to regulate lymphatic pumping function. So the swelling we see in lymphatic organ failure (lymphedema) is immune dysregulation and lymphatic vessel pump failure in the affected body part. The treatment of lymphedema requires moving that fluid out of stagnated areas where there is lymphatic pump failure, in order to restore the immune function carrying the lymph to its proper locations for its lifesaving function. So when an individual has lymphedema, they have organ failure in the lymphatic system noticeable as swelling in the affected part of the body.

COMPLETE DECONGESTIVE THERAPY (CDT) PROVEN EFFECTIVE

When the lymphatic system is non-functioning in the affected part, the pumping function in the tissues has to be externally created by a medical compression device or medical compression garment prescribed after stimulation of the lymphatic system by a specialized form of manual therapy called "Manual Lymphatic Drainage" (MLD). MLD and compression garments are applied by Physical or Occupational Therapists with advanced training as Certified Lymphedema Therapists (CLTs). The total treatment method applied by CLTs is known as Complete Decongestive Therapy (CDT) and includes all components of the method. This method has extensive research over 30 years showing effectiveness when done properly.

COMPRESSION GARMENTS MEET LEGAL DEFINITION OF PROSTHETIC

The Social Security Act requires coverage of prosthetics. Under the legal definition of a prosthetic, the compression garment for lymphedema is a prosthetic: Social Security Act, Title XVIII, Section 1861(s): Medical and Other Health Services (s) The term "medical and other health services" means any of the following items or services: (5) surgical dressings, and splints, casts, and other devices used for reduction of fractures and dislocations; (6) durable medical equipment; (8) prosthetic devices (other than dental) which replace all or part of an internal body organ (including colostomy bags and supplies directly related to colostomy care), including replacement of such devices... (9) leg, arm, back, and neck braces, and artificial legs, arms, and eyes, including replacements if required because of a change in the patient's physical condition;. The Women's Health and Cancer Rights Act (WHCRA) of 1998 requires insurance companies to cover all treatment for complications of mastectomy including lymphedema. But insurance companies cannot get by with only covering compression garments for breast cancer patients because lymphedema (lymphatic failure) occurs from any treatment damaging the lymphatic system or mal-development of the lymphatic system. Insurance companies also cannot exclude coverage of lymphedema compression garments by their DME (Durable Medical Equipment) provision. Lymphedema compression garments are not DME. By the provisions of the Social Security Act, all individuals with lymphedema require the correct lymphatic treatment, CDT, including a lymphatic prosthetic, a medical compression garment.

CDT IS DIFFERENT FROM MASSAGE AND NON-MEDICAL ELASTIC GARMENTS

One problem for the lay public (and insurance company policy writers) in understanding CDT is that the components of CDT appear very much like cheap medical interventions that are actually very different. For example MLD looks like massage but is not massage, rather a specialized form of light skin stretch that stimulates residual lymphatic function. The compression bandages used for lymphedema look like Ace bandages but are Short Stretch Bandages with a different tensile strength. The compression sleeves and stockings look like elastic compression garments used for minor fluid retention but lymphedema medical compression garments are very different. Lymphedema compression garments are fabricated from higher tension fibers and weaves that do not constrict the lymphedema affected part. Inappropriate elastic compression create a "lymphatic tourniquet" that further damages the lymphatic system. Lymphedema compression garments have to be medically prescribed as they have specifications for the severity of the disease. Many times, lymphedema compression garments must be custom-fitted in order to provide correct compression to the affected area. A lymphedema medical compression garment forms a firm "container" on the affected body part to simulate the lymphatic pumping action. The patient's muscle contractions push up against the more rigid container of a lymphatic garment to recreate tissue fluid pumping. Lymphatic compression garments "contain" in order to simulate lymphatic pumping. They do not "squeeze" like an elastic garment.

INSURANCE COVERAGE FOR LYMPHEDEMA TREATMENT

Medical compression bandages, compression devices and compression garments are an integral part of the treatment for lymphedema. Unless an insurance policy excludes coverage for treatment for this disease (lymphedema/lymphatic organ failure) the subscriber must be provided all parts of the evidence-based, medically researched, CDT treatment. It is dangerous to pick apart a multimodal treatment protocol of proven effectiveness by covering one part and not another or substituting ineffective, non-medical devices or treatment of inferior quality arbitrarily with no scientific basis. Due to the requirement for constant wear at all times, and necessary laundering, garments and bandages have a limited life span. Therefore, each patient must have two sets of bandages and/or garments at all times, both of which must be replaced no less than every six months. Patients do need periodic courses of therapy when the condition progresses or loses control in spite of the patient's best efforts. The condition is incurable and requires treatment for life.

THE COST OF NOT COVERING EFFECTIVE LYMPHEDEMA TREATMENT

Insurance companies that fail to provide coverage for the standard treatment of lymphedema, including compression garments, devices and bandages, predispose their customers to serious consequences that ultimately will cost more than covering CDT. Over the years, I have seen many cases of patients with recurrent infections and skin breakdown, entering into a revolving door of hospitalizations and prolonged treatment in wound clinics because they were denied coverage for the correct therapy, compression garment or device. The insurance company ultimately will pay a much higher price for noncoverage of effective treatment of lymphedema.

COST OF A LYMPHEDEMA COVERAGE MANDATE

Attached is a paper published in Health Economics Review (2016) analyzing 10 years experience in the Commonwealth of Virginia with a lymphedema treatment mandate. The author summarized "Ten years of insurance experience with a lymphedema treatment mandate in Virginia shows that costs of lymphedema treatment are an insignificant part of insured healthcare costs, and that treatment of lymphedema may reduce costs of office visits and hospitalizations due to lymphedema and lymphedema-related cellulitis. Estimates based on more limited data overestimate these costs. Lymphedema treatment is a potent tool for reduction in healthcare costs while improving the quality of care for cancer survivors and others suffering with this chronic progressive condition."