



10 THINGS I'D LIKE MY FAMILY AND FRIENDS TO KNOW ABOUT LYMPHEDEMA (LE)

01

SOME STATISTICS

Up to 10 million Americans, and hundreds of millions worldwide, suffer from lymphedema and lymphatic diseases. More people in the U.S. suffer from these diseases than from multiple sclerosis, muscular dystrophy, ALS, Parkinson's disease, and AIDS—combined (source: Lymphatic Education & Resource Network [<https://lymphaticnetwork.org/>]).

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WHAT IS LYMPHEDEMA (OR LE)?

Lymphedema is a lifelong, chronic, and incurable disease. Lymphedema most commonly involves swelling in arms or legs and can affect the head, neck, and trunk.

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HOW DO PEOPLE GET LE?

Most lymphedema occurs after cancer treatment or non-cancer related surgery (secondary lymphedema), but some people are born with it or develop it later in life (primary lymphedema). Lymphedema can happen to anyone of any age.

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HOW SERIOUS IS LE?

Lymphedema is a disruption to the lymphatic system, a major body system that helps clean toxins and debris from the body. If the lymphatic system is not working, there is build-up of a protein-rich fluid. Cuts, scrapes, and insect bites can quickly become infected and require emergency care. Complications from lymphedema, such as infections or cellulitis, often result in long hospital stays.

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HOW IS LE TREATED?

Lymphedema treatment often requires bandaging, compression garments, and lymph drainage massage. Surgical interventions are being developed but are not curative—they are helping some people with improving their condition.

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HOW IS LE MANAGED?

Lymphedema requires lifetime management and vigilant self-care. An early diagnosis means lymphedema can be better managed—but many physicians do not understand this disease or recognize it early. People with chronic swelling need to see a physician with expertise in lymphedema, and/or a Certified Lymphedema Therapist.

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IS LE PAINFUL?

Lymphedema can be extremely painful. In addition to the lymphedema swelling, the individual may also have chronic pain in the affected area. This pain can be severe and debilitating.

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IS LE TREATMENT EXPENSIVE?

Lymphedema treatment causes financial burdens that can be devastating. Compression garments, especially if custom made, lymph drainage massage, and lymphedema therapist visits are expensive. Insurance often does not provide much, if any, coverage.

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WHAT LIFESTYLE CHANGES DOES LE REQUIRE?

Individuals with lymphedema have to modify their activities. For example, they must avoid hot tubs and saunas and do less outdoors in the heat of summer. Some individuals with LE can no longer work, drive a vehicle, serve on a jury, or entertain as they formerly did.

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IS LE MANAGEMENT TIME CONSUMING?

Lymphedema management often requires several hours a day devoted to putting on compression garments, being vigilant about skin care, using a pneumatic compression device (pump), performing self-lymph drainage, and doing special exercises to move the lymph fluid.



Lymphatic Education
& Research Network

LE&RN is a 501(c)3 nonprofit organization located at 261 Madison Avenue, 9th Floor, New York, NY 10016. For more information: www.LymphaticNetwork.org

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