



# 10 THINGS YOU WANT TO KNOW WHEN YOU LEARN YOU HAVE LYMPHEDEMA (LE)

## 01

### WHAT IS LYMPHEDEMA (LE)?

Lymphedema is chronic swelling, most commonly in arms or legs, but it can affect other areas of the body, such as the trunk, head, or neck. LE can be very serious as the affected area can increase in size over time if the swelling is not controlled, and you are more susceptible to infections because lymph fluid drains waste products from your tissues; trapped lymph fluid is not healthy fluid.

## 02

### HOW DO I TREAT LE?

Find a Certified Lymphedema Therapist (CLT) to help you with a management program. The Lymphedema Association of North America (LANA) has a network of CLTs who are dedicated to supporting people with LE. The Lymphatic Research and Education Network (LE&RN) provides a link to "Finding a Lymphedema Therapist" on its website ([lymphaticnetwork.org](http://lymphaticnetwork.org)).

## 03

### HOW DO I STOP LE FROM GETTING WORSE?

A CLT will design a treatment program which includes education, reduction in swelling (bandaging, massage, special exercises), and prescription of compression garments/aids (if required) to help you manage your LE. See a CLT every six to twelve months to make sure you are doing everything you can to stay healthy and to learn new ways to manage your disease.

## 04

### ARE THERE SUPPORT GROUPS FOR LE?

Facebook has several LE support groups. The National Lymphedema Network (NLN) sponsors an online support group on [www.inspire.com](http://www.inspire.com). LE&RN provides a service, "Ask the Experts," so you can contact physicians and therapists directly. Your CLT is likely to know about support groups in your area.

## 05

### WHY DID LE HAPPEN TO ME?

Everyone has a lymphatic system—some people have a system that is more prone to developing LE. LE can be triggered by cancer treatment, lymph node removal during surgery, trauma or infection (secondary lymphedema), or you can be born with an imperfect lymphatic system (primary lymphedema).

## 06

### WHAT ARE THE DOS AND DON'TS OF LE?

Do live normally, but take some extra precautions. Dedicate time each day to managing your LE. Avoid activities that can increase swelling or risk of infection such as extreme heat (hot tubs, saunas); avoid excess alcohol intake; avoid needle stick or blood pressure cuff on the affected limb. Look after your skin, and seek medical advice at the first sign of infection, such as cellulitis, in the LE limb/area.

## 07

### WHAT ARE THE SYMPTOMS OF CELLULITIS?

Symptoms of cellulitis include flu-like feelings, fever, or redness/pain that spreads. Cellulitis causes additional damage to a struggling lymphatic system—early treatment is essential. Seek medical advice immediately even if you're not sure it's cellulitis.

## 08

### ARE THERE SPECIAL DIETS, LOTIONS OR MEDICINES FOR LE?

Visit a dietitian if you have specific questions about your dietary needs. Ask your CLT about skin care as many lotions can dry your skin. If you find something that works for you, it may not work for someone else—but information sharing is a good thing. Just find what works for you.

## 09

### CAN LE BE CURED?

There is no known cure for LE at present. Surgical approaches are available, but not everyone is a suitable candidate for surgery. Drug trials are underway to find medication to improve the function of lymphatic vessels. In the meantime, practice vigilant LE care—protect and nourish your skin, avoid infections, wear compression, and exercise regularly.

## 10

### HOW CAN I LEARN MORE ABOUT LE?

Physicians and healthcare practitioners often have little training in diagnosing and treating LE. Seek out trusted sources for information on the Internet. LE&RN ([LymphaticNetwork.org](http://LymphaticNetwork.org)) has many LE educational programs and links to a variety of resource organizations. NLN ([lymphnet.org/](http://lymphnet.org/)) has position papers on key issues affecting people with LE. LE is different for each individual. Check with your CLT about what might work for you.



Lymphatic Education  
& Research Network

LE&RN is a 501(c)3 nonprofit organization located at 154 West 14th Street, 2nd Floor, New York, NY 10011. For more information: [www.LymphaticNetwork.org](http://www.LymphaticNetwork.org)

**10ThingsLE**

For more information: [www.10ThingsLE.info](http://www.10ThingsLE.info)