



Lymphatic Education
& Research Network

LE&RN RESOURCE GUIDE



At LE&RN, our goal is to bring you all of these resources to help improve the quality of life for people living with lymphatic diseases (LD).

Inside are ways to get educated and connected to the community.

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The **LE&RN Resource Center** is sponsored by



LE&RN RESOURCES

If you're unable to click the links below, try downloading the document.



LE&RN Centers of Excellence (COE)

What it is: A geographically diverse network of local and/or regional clinical centers providing the best possible multi-disciplinary clinical care and services for individuals affected by lymphatic diseases and their families.

How it can help: Need help finding care? Search the list of Centers.

Where to get it: <https://lymphaticnetwork.org/centers-of-excellence>



How to Find a Qualified Lymphedema Therapist

What it is: Find a local certified lymphedema therapist (CLT).

How it can help: We can offer tips on the type of credentials you should look for, and suggest what questions you might ask when selecting a new therapist. You will find several databases that can help you locate a therapist based on your zip code.

Where to get it: <https://lymphaticnetwork.org/living-with-lymphedema/find-a-lymphedema-therapist>



LE&RN Global Registry for Lymphatic Diseases

What it is: Here, people with lymphatic diseases can make a personal commitment to research by sharing their medical history and a bio-specimen.

How it can help: The registry and biorepository are helping scientists collaborate and work toward a cure.

Where to get it: <https://lymphaticnetwork.org/ldregistry>



RECORDING IS NOW AVAILABLE!

LE&RN Video Symposia

What it is: A video library filled with all of LE&RN's Symposia as well as the Harvard Lymphedema Symposia. These presentations from world-renowned doctors and therapists range from personal

care and surgery options, to cutting edge research in lymphatics.

How it can help: Find out about the latest research and best practices in lymphatic disease care.

Where to get it: <https://lymphaticnetwork.org/video-resources>



LE&RN e-News

What it is: Stay up-to-date with the latest news, including LE&RN Online Symposia, *Lymphatic News Monthly*, clinical trials, research alerts, Run/Walk to Fight Lymphatic Diseases event updates, and more, delivered straight to your inbox.

How it can help: Stay connected to the community and find out how—together—we are making a difference.

Where to get it: Just sign up on our website at: <https://lymphaticnetwork.org/subscribe>



Resources About Cancer-Related Lymphedema

What it is: To bring awareness to this disease, and to advocate for prevention and early treatment, LE&RN and the Centers for Disease Control and Prevention (CDC) have joined forces with two celebrities who have experienced LE's effects first-hand: actors Kathy Bates and Steve Guttenberg.

How it can help: Our goal is to equip you with the knowledge and tools to help you understand the best next steps in your journey, including how to get properly diagnosed, advocate for yourself, and to find the best medical professionals.

Where to get it: <https://lymphaticnetwork.org/learn-live>

LE&RN RESOURCES

ASK THE EXPERTS

Ask the Experts

What it is: An online forum that allows you to ask a medical practitioner or therapist questions related to lymphatic diseases.

How it can help: Getting expert answers to your questions is now easy and convenient.

Where to get it: <https://lymphaticnetwork.org/living-with-lymphedema/ask-the-experts/>



FAQ's About Lymphatic Diseases

What it is: Find answers to the most commonly asked questions about lymphatic diseases (LDs).

How it can help: All questions are compiled here in one place and can point you toward our more in-depth resources.

Where to get it: <https://lymphaticnetwork.org/living-with-lymphedema/lymphedema/>



Join A Chapter

What it is: Get involved personally with the lymphatic disease community close to you.

How it can help: Connect with others, share information, and get involved!

Where to get it: State Chapters: <https://lymphaticnetwork.org/chapters>



Your Stories

What it is: Read stories from people with lymphatic diseases and their loved ones who are fighting the battle alongside them.

How it can help: No one with a lymphatic disease should feel isolated. Read these inspiring stories and realize that you are not alone.

Where to get it: <https://lymphaticnetwork.org/living-with-lymphedema/your-stories/>



World Lymphedema Day®
March 6

World Lymphedema Day, March 6

What it is: WLD is an annual advocate-driven celebration to educate the world. It was established in 2016 by the United States Senate in response to a bill written by LE&RN.

How it can help: Connect with local advocates or start an event that welcomes others with lymphatic diseases.

Where to get it: <https://lymphaticnetwork.org/wld>



LE&RN's Virtual Expo

What it is: Find products and services for people living with a lymphatic disease.

How it can help: This expo is open 24/7/365 right from the convenience of your computer.

Where to get it: <https://lymphaticnetwork.org/expo>

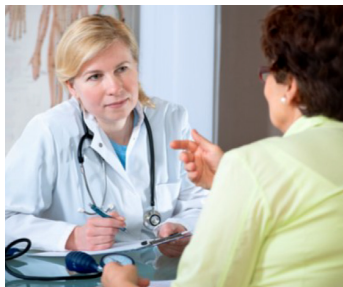
RELATED ORGANIZATIONS

Related Organizations

What it is: A list of organizations that can offer additional resources.

How it can help: Living with lymphatic diseases can be overwhelming; these organizations may be able to help.

Where to get it: <https://lymphaticnetwork.org/living-with-lymphedema/related-organizations/>



10 THINGS I WANT MY PHYSICIAN TO KNOW ABOUT LYMPHEDEMA (LE)

01

LYMPHEDEMA MUST BE DIAGNOSED EARLY.

Lymphedema is a disease that can be hereditary or genetic (primary) or acquired through damage to the lymph system, such as after a surgical procedure, infection, radiation, or other physical trauma (secondary). Referral to a Certified Lymphedema Therapist (CLT) is essential to manage the disease before serious complications occur.

02

LYMPHEDEMA MAY INITIALLY PRESENT AS CHRONIC SWELLING.

A vascular work-up is essential. Once a physician has ruled out other medical conditions, referral to a specialist with expertise in lymphedema is indicated.

03

LYMPHEDEMA AS A POTENTIAL OUTCOME REQUIRES PATIENT EDUCATION.

Patients must be educated about lymphedema risk from the inception of treatment, particularly before undergoing an invasive procedure or surgery in which lymph nodes may be damaged or removed. Educating patients about lymphedema signs/symptoms to be aware of post-operatively should not discourage them from agreeing to surgery.

04

LYMPHEDEMA HAS BOTH PHYSICAL AND PSYCHOLOGICAL EFFECTS.

Lymphedema changes the individual's sense of body image and mobility.

05

LYMPHEDEMA OFTEN CAUSES INDIVIDUALS TO FEEL UNSUPPORTED AND ISOLATED.

Individuals may feel they are part of an invisible population—many physicians do not even recognize the condition.

06

LYMPHEDEMA PATIENTS OFTEN NEED PSYCHOLOGICAL SUPPORT.

Lymphedema has an effect on the individual's emotional health that should not be overlooked. Referral to a mental health professional should be offered.

07

LYMPHEDEMA IS EXHAUSTING AND DISABLING.

Lymphedema alters the individual's ability to participate in activities of daily living; chronic pain and discomfort associated with the disease can be debilitating, exhausting, and depressive.

08

LYMPHEDEMA DECREASES QUALITY OF LIFE.

Lymphedema robs affected individuals of the sense of joy in life; it is incredibly time consuming and expensive to manage on a daily basis.

09

LYMPHEDEMA MANAGEMENT IS COMPLEX AND EXPENSIVE.

Compression garments can be difficult to put on and wear and only last from 4 to 6 months; ongoing treatment is expensive. Physicians and therapists must understand the condition better and exhibit compassion for people struggling with the disease. Most insurance does not cover garment costs, which are higher if the lymphedema is more severe and custom-made compression garments are required.

10

LYMPHEDEMA IS DIFFERENT IN EVERY INDIVIDUAL.

Lymphedema manifests with different signs and symptoms in each individual. Thus, like pain, lymphedema is what the patient says it is.



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10ThingsLE

For more information: www.10ThingsLE.info



10 THINGS MY FAMILY AND FRIENDS CAN DO TO SUPPORT ME AND MY LYMPHEDEMA (LE)

01

LYMPHEDEMA (OR LE) IS OVERWHELMING AND FRIGHTENING.

LE is a lifelong disease that will become worse if not diligently managed. Please help lift my spirits when this “new normal” seems unbearable.

02

LYMPHEDEMA IS A DEBILITATING DISEASE THAT AFFECTS EVERY ASPECT OF MY LIFE.

Please be patient if I struggle to accomplish daily activities. Offer help with these activities, but realize I may want to accomplish them without help to maintain my independence.

03

LYMPHEDEMA IS NOT MY FAULT.

Lymphedema is not obesity or a “fat disease”; it’s a disease of the lymphatic system. Losing weight may improve lymphedema somewhat, but nothing, including losing weight or exercise, will cure it.

04

LYMPHEDEMA AFFECTS MOBILITY AND BODY IMAGE.

Know that I am very aware of these changes when they occur. You can support me best by being sensitive to those body image and mobility issues when inquiring about my health.

05

INDIVIDUALS WITH LYMPHEDEMA MAY NEED SUPPORT TO STAY MOTIVATED.

I may need support to keep wearing compression garments, to stay active, and to eat well. It can be stressful and depressing to wear compression garments that typically are uncomfortable and unattractive. Please be accepting (or supportive) of how I look and feel.

06

DAY-TO-DAY LIFE WITH LYMPHEDEMA IS EXTREMELY VARIABLE, WITH BOTH GOOD AND DIFFICULT DAYS.

Living with the disease is physically and mentally taxing. There will be times that this disease depletes my energy, enthusiasm, and sense of humor. Please be extra supportive on these tough days.

07

LYMPHEDEMA IS BURDENSOME: PHYSICALLY, EMOTIONALLY, AND FINANCIALLY.

Living with lymphedema consumes much of my free time and may prevent me from spending discretionary income on things other than lymphedema management.

08

I MIGHT DECLINE AN INVITATION.

This may be because management of my lymphedema must be my priority.

09

IF MY LYMPHEDEMA IS RELATED TO CANCER TREATMENT:

I may find that activities related to lymphedema management remind me of my cancer history and the possibility of recurrence. Thank you for listening when I tell you about my fears of getting cancer again.

10

EVERY PERSON WITH LYMPHEDEMA HAS A UNIQUE STORY AND SPECIAL NEEDS.

I greatly appreciate it when you ask how you can support me. If you are willing to listen, I will share with you my very personal experience as a person living with lymphedema.



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10 THINGS TO KNOW ABOUT OVARIAN AND GYNECOLOGIC CANCER AND LYMPHEDEMA (LE)

01

SOME STATISTICS

While survival rates among patients with gynecologic cancers have steadily improved, it comes with the risk of a secondary disease—lymphedema. Up to 10 million Americans, and over 250 million worldwide, suffer from lymphedema (LE) and lymphatic diseases (LD). More people in the U.S. suffer from LE/LD than from multiple sclerosis, muscular dystrophy, ALS, Parkinson's disease and AIDS—combined.

02

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.

03

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.

04

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.

05

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.

06

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.

07

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.

08

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.

09

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.

10

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.



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10 THINGS MY CERTIFIED LYMPHEDEMA THERAPIST TAUGHT ME ABOUT LYMPHEDEMA (LE)

01

SELF MANAGEMENT

I can learn to manage my LE with the guidance of my Certified Lymphedema Therapist (CLT). I can do manual lymph drainage (MLD), use a pneumatic compression device (pump), wrap the affected limb, and put on garments.

02

GARMENTS

I can learn how to don and doff (put on and take off) compression garments and, while it is often difficult to adjust to wearing them, it will get easier over time and with practice.

03

INFECTION PREVENTION

I can reduce the risk of infections by using skin products with the appropriate pH (acidic <7.0), treating any cuts, scrapes, or scratches immediately, avoiding routine injections or blood pressure readings in the affected area, and seeking medical care as soon as symptoms of cellulitis (redness, fever, pain) appear.

04

EDUCATION

I can educate myself about lymphedema and also educate the physicians and other healthcare professionals I come into contact with. The CLT will teach me and can advocate for me if I need assistance.

05

EXERCISE AND ACTIVITY

I can exercise anywhere and often to keep the lymph flowing. I can stay active, taking care not to sit or stand still for long periods of time.

06

HYDRATION AND NUTRITION

I can manage my diet by eating healthy foods, avoiding sugars and salt, if indicated, and drinking adequate amounts of water daily.

07

ADJUSTING TREATMENT PLANS

I can tweak my treatment program from time to time. I should see my CLT every 6 to 12 months to get advice about new ideas and review of my compression garments. My goal is to reach the point where I have the best control with the least effort, knowing that differs for each person with LE.

08

ELEVATION

I can keep my feet elevated during the day as much as possible and overnight too by elevating the end of the bed, using a wedge, or placing pillows under my legs. If the LE is in my arm, I can sleep with my arm on a pillow.

09

EMOTIONS AND ATTITUDE

I know that LE is overwhelming at first but will get easier over time. I can get support from online groups of individuals with LE, from my CLT, friends and family, and mental healthcare professionals to help me cope with this lifelong disease.

10

ONGOING ASSISTANCE

I know if I ever have a question or concern, I can contact my CLT for advice. I also know if the CLT is not listening to or helping me, I have the right to find another CLT.



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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).

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. 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) has many LE educational programs and links to a variety of resource organizations. NLN (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.

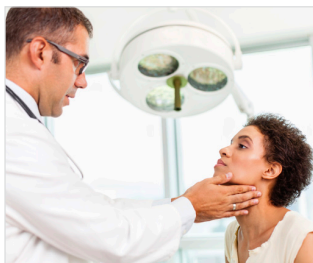


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10 THINGS TO KNOW ABOUT CANCER AND LYMPHEDEMA (LE)

01

WHAT PERCENTAGE OF CANCER SURVIVORS GET LYMPHEDEMA (LE)?

While survival rates among patients with cancers have steadily improved, it comes with the risk of a secondary disease—lymphedema. Up to 10 million Americans are estimated to have lymphedema—seven million of which are a result of cancer treatment. This includes the following percent estimates: breast (30%); sarcoma (30%); gynecological (20%); melanoma (16%); genital urinary (10%); head and neck (75%).

02

WHAT IS LYMPHEDEMA (LE)?

Lymphedema is a lifelong, chronic, and incurable disease. Lymphedema most commonly involves swelling in arms or legs and can affect the head, neck, trunk, and genital area. It occurs after cancer treatments, non-cancer related surgery, or trauma to the lymph nodes (secondary LE), while some people are born with it or develop it later in life (primary LE).

03

WHY ARE CANCER PATIENTS AT RISK?

Treatment plans such as cytoreductive surgery, extensive node dissection, lymph node removal, and radiation can all cause a disruption to the lymphatic system running the risk of lymphedema. With the surgeon's goal of eliminating cancer, development of LE is often not even discussed with patients.

04

PATIENT EDUCATION IS CRUCIAL

Patients must be educated about lymphedema risk from the inception of treatment, particularly before undergoing an invasive procedure or surgery in which lymph nodes may be damaged or removed. Educating patients about LE signs/symptoms to be aware of post-operatively should not discourage them from agreeing to surgery or other treatments.

05

IS THERE FURTHER RISK AFTER SURGERY?

Lymphedema can occur months to years following surgery or treatment for cancer with lymph node involvement. Reoccurrence of the tumor or metastasis of cancers increase the risk of lymphedema by further impairing lymph drainage.

06

SHOULD MY DOCTOR BE DOING ANYTHING PRE- AND POST-SURGERY?

Measurements of the affected area (i.e., pelvis, lower or upper limbs) are needed both pre- and post-operatively. Referral to a Certified Lymphedema Therapist (CLT) as soon as changes are detected is essential to manage the disease before serious complications occur.

07

LYMPHEDEMA MANAGEMENT CAN BE COMPLEX AND EXPENSIVE

Compression garments can be difficult to put on and wear and only last from 4 to 6 months; ongoing treatment is expensive. Most insurance does not cover garment costs, which are higher if the lymphedema is more severe and custom-made compression garments are required.

08

LYMPHEDEMA CAN BE EXHAUSTING AND DISABLING

Lymphedema alters the individual's ability to participate in activities of daily living; chronic pain and discomfort associated with the disease can be debilitating, exhausting, and depressive.

09

LYMPHEDEMA MAY DECREASE QUALITY OF LIFE

Lymphedema robs affected individuals of the sense of joy in life; it is incredibly time consuming and expensive to manage on a daily basis.

10

LYMPHEDEMA MAY CAUSE INDIVIDUALS TO FEEL UNSUPPORTED AND ISOLATED

Individuals may feel they are part of an invisible population since physicians and medical practitioners often fail to correctly diagnose and treat the disease. Although treatment centers are currently few, there are a variety of resources available on the LE&RN website; e.g., a current list of LE/LD treatment centers, resources to help you find a therapist, stories of others living with LE/LD, free symposium videos, and LE&RN's social media connecting you to the LE community.



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10 THINGS TO KNOW ABOUT PREVENTING CHRONIC, CANCER-RELATED LE OF THE ARMS AND LEGS

01

CHRONIC CANCER-RELATED LYMPHEDEMA (LE) IS A LIFELONG CONDITION

Lymphedema (LE) occurs when the lymphatic system that removes waste from the body becomes damaged or impaired. Fluid builds up and causes swelling in your arms, legs, hands, or feet. Your arm, leg, hand, or foot may feel heavy, feel tight, or be hard to move. If left untreated, lymphedema may lead to complications including infection. You may have to manage lymphedema with therapy or lifestyle modification for the rest of your life.

02

THE RISK OF GETTING LYMPHEDEMA DEPENDS ON YOUR CANCER TYPE AND TREATMENT

Up to 10 million Americans are estimated to have lymphedema—seven million of which are a result of cancer treatment. This includes the following percent estimates: breast (30%); sarcoma (30%); gynecological (20%); melanoma (16%); genital urinary (10%); head and neck (75%). Cancer treatments such as surgery, radiation, or chemotherapy can increase your risk of getting lymphedema.

03

CANCER-RELATED LYMPHEDEMA IS PREVENTABLE

Cancer-related lymphedema of the arms and legs develops in stages. When it is caught early, before you feel or can measure noticeable swelling, it can be treated and stopped before it gets worse and becomes a lifelong condition.

04

EARLY DETECTION IS CRITICAL

In order to prevent the development of chronic lymphedema, it must be caught early before you notice much swelling. In order to catch lymphedema early, you must be routinely tested when you see your doctor or therapist. *Bioimpedance spectroscopy* (BIS) is one method used by doctors and therapists to help find signs of lymphedema early, before you notice symptoms yourself.

05

PREVENTION STARTS BEFORE CANCER TREATMENT BEGINS

Measurements of your arms or legs before cancer-treatment begins gives your doctor or therapist a baseline value of what is normal for you. Any changes after your cancer treatment can be compared to your baseline measurement. This way, your doctor or therapist can detect lymphedema at the earliest possible stage.

06

AT-HOME THERAPY CAN HALT THE DEVELOPMENT OF CHRONIC LYMPHEDEMA

If your doctor or therapist finds signs of early lymphedema, they may prescribe at-home treatment. Your treatment plan may include wearing compression garments, light stretching, or self-massage.

07

EVIDENCE SUPPORTS EARLY DETECTION AND TREATMENT

Clinical trials have shown that early detection and treatment of cancer-related lymphedema can prevent it from becoming a chronic condition.

08

LEADING GUIDELINES RECOMMEND A PREVENTION MODEL-OF-CARE

Early detection and treatment of lymphedema to improve patient outcomes is recommended in multiple clinical practice guidelines, including: American Physical Therapy Association (APTA), *eviCore* Clinical Guidelines for Physical and Occupational Therapy Service, National Accreditation Program for Breast Centers (NAPBC), National Comprehensive Cancer Network (NCCN) Guidelines for Breast Cancer, National Comprehensive Cancer Network (NCCN) Guidelines for Survivorship, and National Lymphedema Network (NLN).

09

PREVENTION IS HAPPENING NOW

Many cancer treatment centers, both large and small, have implemented programs to prevent cancer patients from getting chronic lymphedema. LE&RN's *Centers of Excellence* are required to offer risk reduction and surveillance programs for high risk patients and assessment tools such as *perometry* or *Bioimpedance spectroscopy* (BIS). Learn more: [LE&RN Centers of Excellence](#)

10

RESOURCES ARE AVAILABLE TO YOU

Now that you know more about preventing cancer-related lymphedema of the arms or legs, you can be prepared to talk to your doctor or therapist. Print this list, take it with you to your next visit, and ask what they will do to reduce the risk that you develop chronic lymphedema following your cancer treatment.



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10 THINGS TO KNOW ABOUT LIPEDEMA

Lipedema is a chronic fat and lymphatic disorder characterized by an abnormal and disproportionate accumulation of fat in certain areas of the body, typically the hips, thighs, and legs while sparing the trunk. In some people with lipedema, the arms are also impacted, though usually not in isolation. Beyond the physical symptoms, which will be described in more detail, lipedema can also affect quality of life, and present emotional or psychological challenges such as body image concerns, self-esteem issues, or mental health struggles.

Here are 10 common signs and symptoms that can indicate the presence of lipedema:

01

LIPEDEMA MAY RESULT IN DISPROPORTIONATE FAT DISTRIBUTION

Lipedema causes symmetrical enlargement of the lower body, with fat accumulation in the hips, thighs, and sometimes extending to the ankles. The upper body is usually unaffected, although the arms may also be impacted in some cases. The hands and feet are typically not affected until later stages of progression.

02

LIPEDEMA IS KNOWN FOR COLUMN-LIKE OR BRACELET APPEARANCE IN THE LIMBS

Lipedema can create a distinct band-like appearance around the ankles or wrists, resembling bracelets or tight socks. This is known as wrist or ankle “cuffing.” Lipedema can also lead to column-like legs or “tree trunk” legs, with the calves sometimes being the same size as the thighs.

03

LIPEDEMA MAY LEAD TO PAIN AND HYPERSENSITIVITY

Lipedema can cause varying levels of pain or heightened sensitivity in the affected areas, earning it the name “painful fat disorder.” Discomfort can range from mild to severe and may worsen with pressure or occur without a clear trigger. Activities such as sitting with pressure on the legs or using blood pressure cuffs on the arms can cause pain. In addition to pain, lipedema can lead to hypersensitivity in the impacted areas, making actions like wearing tight clothing or receiving gentle touch uncomfortable. While the exact cause of pain and hypersensitivity in lipedema is unknown, certain management options may provide relief for this symptom.

04

LIPEDEMA CAN CAUSE EASY BRUISING

Lipedema can cause easy bruising in affected areas, even from minor bumps or pressure. Bruises may appear without any recollection of impact or injury. This is due to blood vessel fragility in the lower body or arms, where non-painful impacts can damage blood vessels and lead to bruising. Even minor bumps or pressure can result in noticeable bruises that take longer to heal.

05

LIPEDEMA MAY PRESENT WITH NODULES AND LOBULES

In lipedema, fat in affected areas can feel grainy or bumpy, resembling seeds, rice, or firm lumps of varying sizes. This texture is caused by fibrotic nodules, thick scar tissue deposited within the fat. These nodules can be present even when the skin appears smooth, but over time, the skin may develop a dimpled or mattress-like appearance, similar to cellulite. As lipedema progresses, fat buildup can create lobules or pockets of fat and skin that hang over the tissue, resulting in “folds” or “saddlebags.”

06

LIPEDEMA MAY NOT IMPROVE WITH CONVENTIONAL DIET OR EXERCISE

Conventional dieting and exercise have little effect on reducing fat in lipedema-affected areas. Extreme measures like bariatric surgery or starvation may lead to fat loss in other parts of the body, but not in the areas affected by lipedema, potentially exacerbating the imbalance. However, nutritional management and gentle activity are still recommended. Some approaches, such as low carb/ketogenic diets, have shown benefits in terms of reducing limb volume, alleviating pain, and enhancing quality of life, even though they may not completely eliminate lipedema tissue.

07

LIPEDEMA COULD BE CONNECTED TO FAMILY HISTORY

Lipedema may be genetically influenced, although the specific gene involved has not been identified. Women with lipedema often have family members who also have the condition, indicating a potential genetic component. This can include relatives like sisters, mothers, or aunts, and even fathers can be carriers. While a family history of similar symptoms increases the likelihood of lipedema, its absence does not rule out a diagnosis. The interaction between genetics and environmental factors in lipedema is still under investigation.

Continued ►

08

LIPDEMA MAY BE INFLUENCED BY HORMONAL STATUS

Lipedema symptoms often emerge or intensify during hormonal changes like puberty, pregnancy, or perimenopause, primarily affecting women. This indicates a potential hormonal influence on lipedema. Although the exact mechanism is unknown, it is advisable to pay extra attention to managing lipedema symptoms during these significant stages in a woman's life.

09

LIPDEMA MAY CAUSE EDEMA (SWELLING)

Lipedema often causes swelling, particularly in the lower legs, which tends to worsen towards the end of the day or in hot, humid conditions. However, the swelling typically resolves overnight. Recent studies indicate increased fluid accumulation in early stages of lipedema, but the lymphatic system compensates by transporting fluid more efficiently. Without proper treatment, lymphatic issues can progress to advanced stages and lead to lymphedema. Early intervention can promote lymphatic health and help prevent this progression.

10

LIPDEMA CAN LIMIT MOBILITY

As lipedema advances, it can limit mobility and range of motion. Excessive fat accumulation alters gait, leading to discomfort and pain while walking. Over time, it becomes challenging to engage in physical activities involving the lower body, such as walking, climbing stairs, or other movements. Fatigue and muscle pain are also common symptoms, even with minimal activity. Due to sensitivity to impact and difficulty with intense exercise, gentle activities like aquatic exercises, stretching, and yoga are recommended to maintain muscle mass, mobility, and support lymphatic function.

SPECIAL NOTE:

It's important to note that these signs and symptoms are not exclusive to lipedema and can also occur in other conditions. If you suspect you may have lipedema, it's crucial to consult with a healthcare professional for an accurate diagnosis and appropriate treatment. A Provider Directory is available: <https://lipedemaproject.org/lipedema-lipoedema-lipodem-provider-directory/>



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10 THINGS MY FAMILY AND FRIENDS SHOULD KNOW TO SUPPORT ME AND MY LIPEDEMA

01

LIPPEDEMA IS NOT MY FAULT

Lipedema is a complex disorder that affects both the fat and lymphatic systems. It is not caused by obesity and has widespread effects on the body. While management is possible, there is no known cure, and surgery may not be accessible to everyone. Please understand that I am doing my best to navigate this challenging condition, and your support without blame or judgment is crucial in my journey.

02

WEIGHT LOSS IS COMPLEX WITH LIPEDEMA

Living with lipedema involves trying various diets, exercise routines, and even surgery. Suggestions for more diets may be frustrating, as they may not be effective for my condition. Lipedema reduction surgery is not an easy way out, but a legitimate option.

03

LIPPEDEMA AFFECTS EVERY ASPECT OF MY LIFE

Managing it is time-consuming and mentally draining. Please understand if I decline invitations or ask for help. It may feel like a full-time job, leaving me with little time and energy. Your patience and support are appreciated.

04

LIPPEDEMA CAN LIMIT MOBILITY

Fat accumulation, fatigue, and pain can restrict physical abilities. I may struggle or be unable to do certain things. Please be sensitive when planning activities together, providing rest opportunities and understanding if I need more time or can't participate fully.

05

INDIVIDUALS WITH LIPEDEMA MAY NEED SUPPORT TO STAY MOTIVATED

Having lipedema can be frustrating, mentally taxing, and demoralizing. I may struggle with keeping up with management. Even smaller struggles may weigh on me, such as finding compression garments that are comfortable and fashionable, getting them on and off by myself, or just keeping up with day-to-day self-care.

06

LIPPEDEMA BRINGS BOTH GOOD AND DIFFICULT DAYS

It is physically and mentally taxing, with no breaks. On challenging days, I may feel depleted and struggle with the weight of a chronic condition.

Please provide extra support and understand that I may not openly express my struggles. Celebrate victories with me and be there during tough times. Lipedema is a rollercoaster, and knowing I have loved ones who support me is invaluable.

07

LIPPEDEMA MANAGEMENT IS EXPENSIVE

Costs for compression garments, therapy, surgery, and pain management are often not covered by insurance. Understanding my limited income and being supportive of low-cost activities can alleviate my financial stress and social isolation.

08

LIPPEDEMA MAY LIMIT MY EATING CHOICES

Nutritional management is a lifelong strategy to manage symptoms and slow progression. Please understand that it's not a temporary diet and that I may struggle in social situations. Support me by understanding my plan, providing compliant options, and not pressuring me to eat off-plan. Remember that my nutritional strategy is about more than weight and has a direct impact on my symptoms.

09

LIPPEDEMA CAN AFFECT BODY IMAGE

Changes in body shape, skin appearance, and potential disfigurement can make me feel "different." Even in the early stages, I may be sensitive to comments about my hips and legs. I may face bias and judgment from others, including medical professionals. Understanding that my body image struggles stem from processing the impact of lipedema is appreciated. Please support me when facing judgment and be mindful of how you discuss size and weight, as it can affect me even if I don't express it.

10

EVERY PERSON WITH LIPEDEMA HAS A UNIQUE STORY AND SPECIAL NEEDS

I appreciate your understanding that lipedema is just one aspect of my life, and I have my own thoughts, needs, and struggles. I may choose to share my experiences but might feel uncomfortable discussing them. Thank you for being open to learning about lipedema and recognizing that my experience may differ from what you've learned. Supporting me means understanding my individual needs and being receptive to what I'm willing to share without judgment.

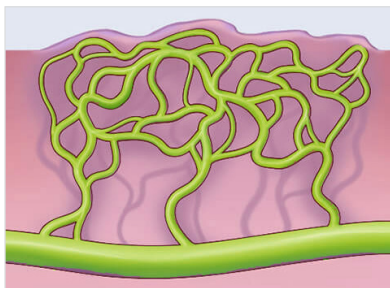


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10 THINGS TO KNOW ABOUT VASCULAR AND LYMPHATIC ANOMALIES

SIMILARITIES AND DIFFERENCES

01

VASCULAR ANOMALIES ARE CLASSIFIED INTO TWO MAJOR GROUPS: TUMORS AND MALFORMATIONS

Vascular anomalies encompass a diverse spectrum of disorders comprising blood vessels from the circulatory system, which may involve arteries, veins, lymphatics, capillaries, or a combination thereof. The *International Society for the Study of Vascular Anomalies (ISSVA)* is responsible for the standard classification of vascular anomalies.

02

VASCULAR TUMORS ARE FORMED FROM BLOOD VESSELS

Vascular tumors are a group of tumors that originate from blood vessels in the body and are present in skin, soft tissues, organs, and bones. Vascular tumors are different from vascular malformations, although both may sometimes occur in one person. Benign vascular tumors will resolve on their own and do not cause any harm. However, malignant vascular tumors, such as vascular cancers, can create serious health problems.

03

VASCULAR MALFORMATIONS ARE THE GROWTH OF ABNORMALLY FORMED ARTERIES, VEINS, LYMPHATICS, OR CAPILLARIES

There are several different types of vascular malformations, and they are named based on the specific type of blood vessel involved such as lymphatic malformation. Vascular malformations are present at birth and enlarge with the child's growth until puberty or pregnancy, when they grow more than the rest of the body.

04

COMPLEX VASCULAR ANOMALIES ARE ALSO KNOWN AS COMBINED VASCULAR ANOMALIES

Complex or combined vascular anomalies can occur anywhere in the body, including the skin, muscles, bones, or internal organs. Sometimes, people living with complex vascular anomalies may also have overgrowth of affected parts of the body.

05

LYMPHATIC ANOMALIES ARE DIAGNOSED WHEN A VESSEL ABNORMALITY ONLY INVOLVES LYMPHATICS

A lymphatic anomaly is the growth of abnormal lymph vessels that leads to fluid-filled lymphatic tissue that gathers and collects. And just like vascular anomalies, they can be classified as a tumor or malformation. Lymphatic tumors include kaposiform hemangioendothelioma and lymphangiosarcomas. Lymphatic malformations are benign anomalies made up of abnormal lymphatic vessels that are non-cancerous and are most common in the head and neck. However, they may develop anywhere in the body.

06

THERE ARE FOUR SUB-TYPES OF COMPLEX LYMPHATIC ANOMALIES

The hallmark of complex lymphatic anomalies is the abnormal development and proliferation of lymphatic vessels that form cysts, masses, and/ or tumors anywhere in the body, in bones and organs. The four sub-types of complex lymphatic anomalies include generalized lymphatic anomaly, Gorham-Stout disease, central conducting lymphatic anomaly, and kaposiform lymphangiomatosis.

07

SYMPTOMS OF COMPLEX LYMPHATIC ANOMALIES DEPEND ON LOCATION AND SIZE

Common symptoms include soft compressible lumps or swellings, visible skin discoloration, recurrent infections such as pneumonia, pain, decreased appetite, shortness of breath, fatigue, problems with mobility, or difficulty in the functioning of a limb, a fluid collection that occurs in the chest and/or belly, and possible bleeding or formation of blood clots, swelling of an extremity possibly leading to lymph leaking from the skin and other areas.

08

DOCTORS CAN STRUGGLE TO DIAGNOSE COMPLEX LYMPHATIC ANOMALIES

Diagnosing complex lymphatic anomalies can be challenging due to their rarity, symptom overlap with common diseases, limited exposure for doctors, and the requirement of specialized diagnostic tests often accessible only in major city centers.

Continued ►

09

COMPLEX LYMPHATIC ANOMALIES ARE TREATABLE

While complete cures do not exist and only partial treatments are available, there are various approaches to enhance the quality of life and provide relief to people living with complex lymphatic anomalies. Treatment options may include interventional radiology, which involves embolization to obstruct blood or lymphatic flow to the malformation, sclerotherapy to inject substances for vessel shrinkage, surgical removal employed cautiously by a multidisciplinary team, laser therapy, or utilization of an expanding selection of medications. These drugs are showing great promise and help to improve symptoms.

10

THERE IS NO CURE FOR VASCULAR ANOMALIES AT THIS TIME

A complete cure for vascular anomalies is not available yet. However, various treatment modalities can help manage the symptoms, reduce the size of the malformation or tumor, and improve the overall quality of life for affected individuals. A vascular anomaly can cause significant health problems and complications. Complications may become life-threatening, including lung, heart, and abdominal fluid collections, recurrent infections, bleeding, blood clots, impaired organ function, lymphedema, or aesthetic concerns. Early diagnosis and appropriate treatment are critical for improved outcomes. Seek expert advice from specialists who deliver care for those living with a vascular anomaly.



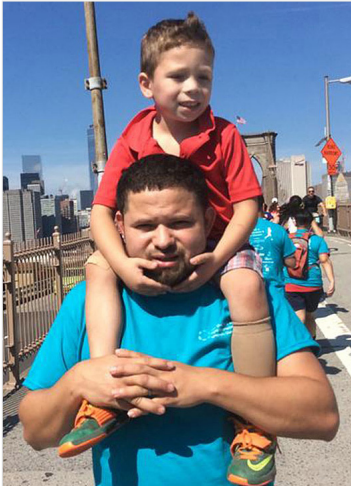
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