

Disclosures & Acknowledgements Disclosures & Acknowledgements



Disclaimer:

- This presentation is a brief introduction to this topic
- Any level of certification requires at least 45 hours of specific training
- Lovers of lifelong learning will relish this area of expertise; it is constantly advancing! So exciting! But....
- Please do not assume you can claim to treat lymphedema based on this presentation; obtain additional training if inspired here to be sure always to

DO NO HARM!



Lymphedema

Hope you watched Nicola's amazing video!

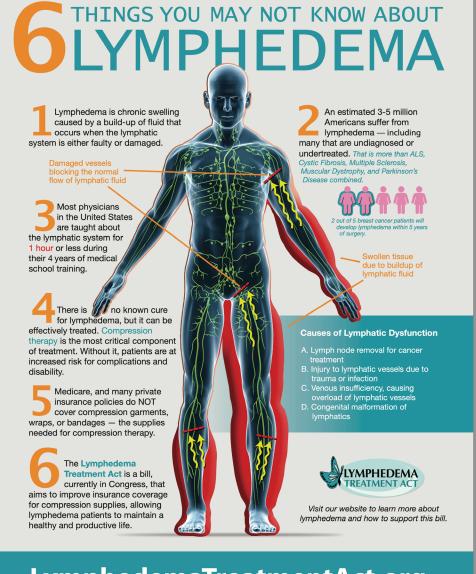
- An abnormal accumulation of protein rich fluid and cells in the subcutaneous tissue, usually in a limb
- Often a result of cancer treatments
 - Surgery
 - Radiation
 - Chemotherapy
- May also be due to trauma, infection
- Most common in US thought to be post BC, or phlebolymphedema
- Most common world-wide is parasite



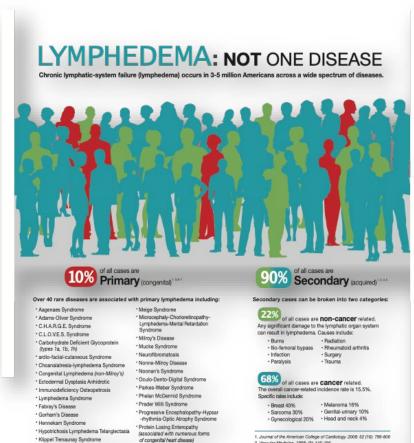
Images courtesy of Guenter Klose



- Occurs when system is faulty or damaged
 - Can be primary
- 3-5 million Americans + affected
- Most physicians not taught in detail re: system
- No known cure, but effective treatment
 - Compression is the most important component
- Medicare and others do not cover compression
- The Lymphedema Treatment Act seeks to improve this



LymphedemaTreatmentAct.org



· Klippel-Trenaunay-Weber Syndrome

· Lymphedema Distichiasis Syndrome

· Macrocephaly-Capillary Malformation Maffucci Syndrome

Lymphedema Myelodysplasia (Emberger Syndrome)

Lymphedema Praecox

* Lymphedema-Distichiasis

· Lymphedema Tarda

* Lipedema

* Proteus Syndrome

* Trisomy 13,18,21

*Turner's Syndrome

W.LL.D. Syndrome

Velocardiofacial Syndrome

Thrombocytopenia with Absent Radius Syndrome

* Spina bifida

1. Journal of the American College of Cardiology, 2008; 52 (10): 799-806 2. Vascular Medicine. 1988: (3): 145-156

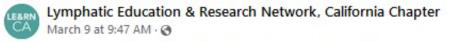
3. Clinical Genetics, 2010; 77; 438-452 4. Cancer, 2010; 116; 5138-49

Journal of Clinical Oncology, 2009: 27:(3): 350-7
 Annels of the New York Academy of Sciences, 2008: 1131: 147-154
 European Journal of Cancer Care, (Engl.) 1996; 5: 56-59

LYMPHEDEMA TREATMENT ACT

LymphedemaTreatmentAct.org

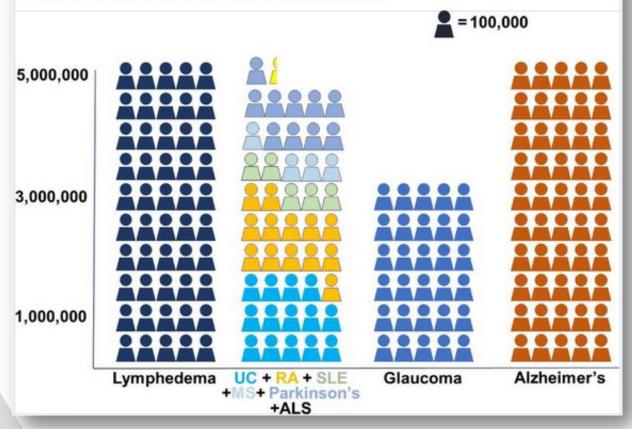




The number of people in the USA who suffer from lymphedema vs. other common chronic diseases. It's time that the medical community became more educated about lymphedema and the insurance companies paid for the essential treatment like they do for other common chronic diseases.

Ulcerative colitis (UC); rheumatoid arthritis (RA); systemic lupus erythematosus (SLE); multiple sclerosis (MS); amyotrophic lateral sclerosis (ALS).

https://www.sciencedirect.com/.../pii/S193152441930074X





Chronic Edema = lymphedema

- Results from damage to the lymphatic system
- May be due to cancer treatment, trauma, infection, congenital issues

Transient Edema = edema that will resolve

 Result of an acute injury, postsurgical, acute infection

Is all edema lymphedema?

- Yes (Lymph+Edema) and no. Depends on your definition of "lymphedema"
- All involves lymphatic fluid
- I define Lymphedema as chronic. But this is tricky.

EDEMA VS. LYMPHEDEMA

EDEMA	LYMPHEDEMA
Edema is the body's normal response to an injury such as a	<i>Lymphedema</i> is condition that occurs when the lymphatic
sprain. As healing progresses, the excess fluid leaves the	system is impaired to the extent that the amount of
	lymphatic fluid within a given area exceeds the capacity of
	the lymphatic transport system to remove it.
Edema is usually caused by excess tissue fluid that had not	Lymphedema is swelling caused by excess protein-rich
yet returned to the circulatory system.	lymph trapped within the tissues.
Edema due to an injury, such as bumping into something,	Lymphedema impaired tissues respond to injury with
is caused by additional tissue fluid coming into the area to	slow healing and/or a potentially serious infection.
help with healing.	
Edema is also caused by circulatory system problems, such as	Lymphedema is caused by damage to the lymphatic
chronic venous insufficiency, and this swelling usually occurs	system. This swelling occurs near the affected area.
in the lower areas of the body.	
Edema swelling does may not leave a mark when a finger is pressed into it. This is known as nonpitting edema.	Lymphedema swelling leaves a mark when a finger is pressed into it. This is known as pitting edema. This occurs only in the early stages of lymphedema.

Originally from Lymphnotes.com, borrowed from https://thelymphielife.com/2012/03/31/lymphedema-vs-edema/



4 Stages of lymphedema:

Latency stage. The system is damaged but no signs of edema present.

Stage 0:

- Patient may report some sense of heaviness, tingling, pain, discomfort
- May exist for weeks, months or years before progressing, and may not progress

Stage 1:

Mild swelling

- Usually pitting is present
- Resolves with rest or elevation "spontaneously reversible"

Stage 2:

Swelling does not go away with rest, elevation

- Early fibrotic changes
- Later in this stage, may or may not pit
- Increased risk of infections

Stage 3:

Hard, fibrotic tissue

- Pitting absent
- Changes include skin thickening, hyperpigmentation, fat deposits, warty overgrowths, skin folds

STAGE ZERO STAGE ONE STAGE TWO STAGE THREE Arm photos courtesy of Dr. Charles McGarvey and Guenter Klose, Leg photos from Mihara M, et al. Pathological Steps of Cancer-Related Lymphedema: Histological Changes in

Treatment of Lymphedema



Complete/Complex
Decongestive Therapy (CDT)

- Manual Lymphatic Drainage
- Compression
- Appropriate exercise
- Skincare
- Also risk reduction, nutrition, education



Lack of consensus on best practices for MLD

- Amount of pressure, effectiveness, frequency, rerouting
- Beneficial to have done mechanically or not?



Lack of consensus on preventative practices:

Can we use ipsilateral limb for needle sticks? BP readings? Blood draws?



CONSIDERATIONS FOR MASSAGE THERAPISTS:

In **non-affected** areas:

01

- General massage is safe
- Beneficial to mimic considerations for damaged quadrant
- Generally best to avoid encouraging local inflammation unless trained in special techniques

In the damaged quadrant:

02

- Avoid cross-fiber friction
- Avoid aggressive deep tissue techniques
- Avoid creating localized inflammation

Consider directionality

- Treat from distal to proximal
- Aim treatment toward regional nodes
- Think parasympathetic stimulation
- Use rhythmic and repetitive slow strokes
- Skin stretch is needed to increase uptake from interstitium





Compression in Phase I





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Materials for Compression in Phase I







Compression in Phase II

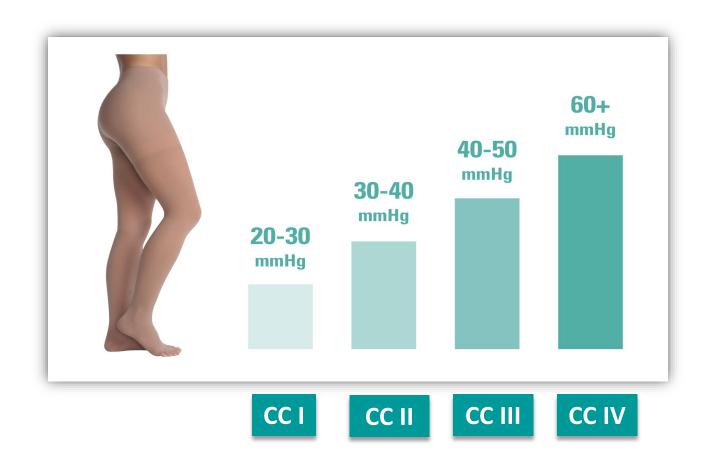


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Compression in Phase II

- These classes are general; vary from US to Europe, circular to flat knit
- Think about how hard it is to put on control pantyhose
- CCIV here would be extremely difficult to don
- There are different knits, garments can be layered
- There are devices to help with donning/doffing







Compression in general (healthy system)

18-21 mmHg, 20-30 mmHg

Can help with leg pain

Can prevent DVT

May increase stamina for those with standing jobs (Oncology MT?)

May prevent spider veins, edema, fatigue, foot pain

Can be a variety of compression amount personal choices per comfort

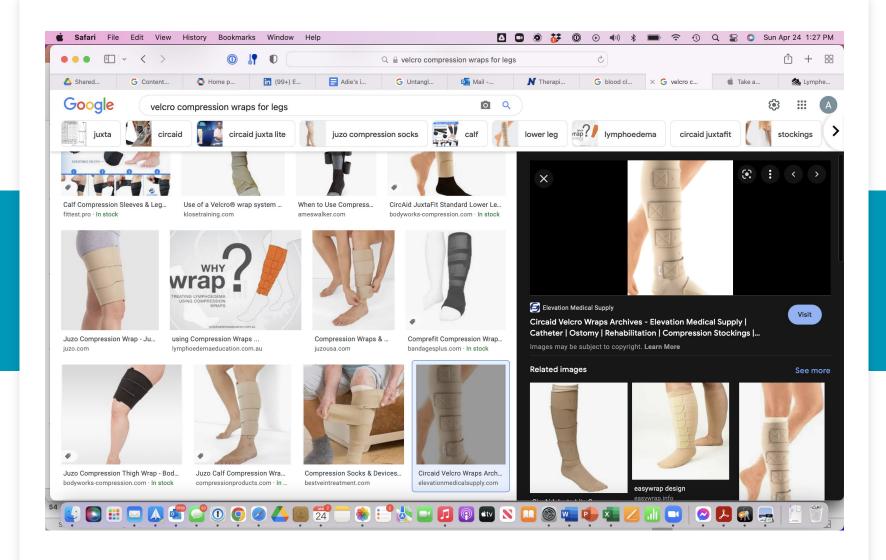
Should always be properly fitted!

Can be pretty and stylish!





Night and alternative compression

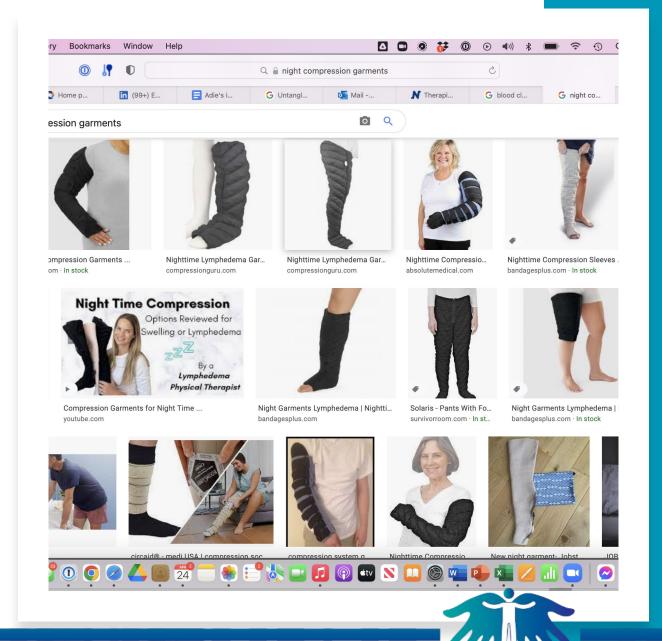


Alternative wraps: may use instead of bandaging

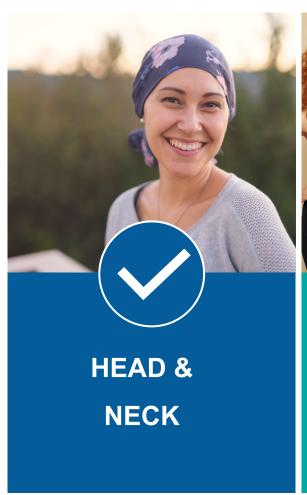


Night garments:

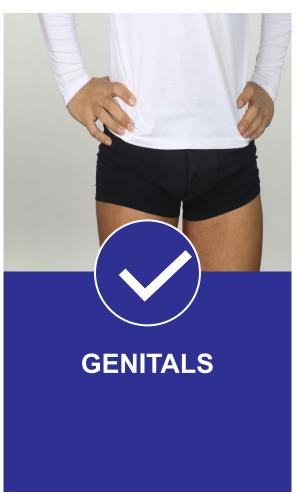
- Too many to list
- See Kelly's video
- Alternative wraps can work
- Not needed for everyone
- Some use <u>instead</u> of daytime compression



Affected areas can also include:









What is Lipedema?

- Disproportionate deposition of fat to the lower half of the body
- Hypersensitivity/ Pain
- **Easy bruising**
- Orthostatic edema progressing to Lymphedema
- Widely believed to be resistant to diet



The look of Lipedema & 5 characteristics:

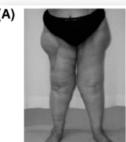
- It can be inherited
- It occurs almost exclusively in women
- It can occur in women of all sizes, from seriously underweight to morbidly obese
- It involves the excess deposit and expansion of fat cells in an unusual and particular pattern –
 - bilateral, symmetrical, usually from the waist to a distinct line just above the ankles
- Unlike the "normal" fat of obesity, lipedemic fat cannot be lost through standard diet and exercise



Stages and Types of Lipedema

Stages of Lipedema

- **Stage 1:** Smooth, soft skin, enlargement of hypodermis
- Stage 2: Skin indented over palpable pea-sized nodules
- Stage 3: Folds and divots over deforming larger fat masses
- Stage 4: Concomitant lymphedema (Lipolymphedema)



A





Type I
Lipedematous
tissue around
hips and
buttocks

Type II
Hips to knees
distribution of
lipedematous
tissue

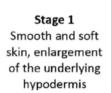
Type III

Hip to ankle phenotype (black arrow: cuff sign)

Type IV

Additional involvement of the upper extremity (with or without lower extremity)







Stage 2
Skin indented over palpable pearlsized nodules ("peau d'orange")



Stage 3 Folds and divots over deforming, larger fat masses



Stage 4 Concomitant lymphedema (lipolymphedema)

Types of Lipedema

- Type I: Hips and buttocks
- Type II: Hips to knees
- Type III: Hip to ankle (see cuff)
- Type IV: Involvement of UE
 - Can have a combination

Treatment Of Lipedema/ Lipolymphedema

MLD and compression are often ameliorating

Lifestyle changes such as a low carb diet are showing to be effective

When progressing to Lipolymphedema, standard lymphedema care is usually applied (CDT)

Every case here, as in all others, is unique and requires clinical judgement

If treating these patients, it is helpful to take advantage of resources provided in this presentation.



Dercum's Disease

https://m.facebook.com/FatDisorders

Often diagnosed concurrently with Lipedema





Painful nodular fat, often lipomas

Rare disorder





3 Types:

- Diffuse-small nodules in fat all over body
- Nodular-larger nodules, lipomas, angiolipomas. Can be disfiguring
- Mixed-both types of nodules present

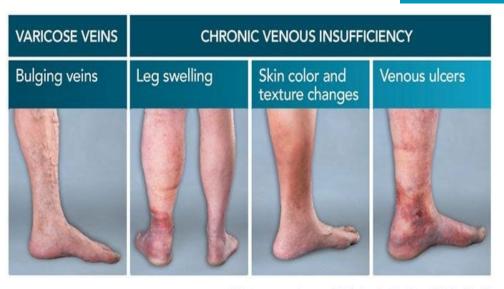
Photo credit: Getty Images Signature



Conditions That May Require Referral

Chronic Venous Insufficiency

- Occurs when the veins and muscle pump activity become incompetent
- May be caused by numerous factors:
 - Repeated damage to veins
 - Lack of adequate activity
 - Obesity
 - Smoking
 - Age
 - Pregnancy
 - *May lead to venous ulcers-refer to MD



Photos courtesy of Rajabrata Sarkar, M.D., Ph.D.



Phlebolymphedema:

"Phlebolymphedema is the most common form of lymphedema in the Western world. It is a combined lymphatic and vascular condition that causes inflammation and lymphedema in the feet and lower legs. It begins with chronic venous insufficiency (CVI) in which the one-way valves in the veins of the lower legs lose the ability to completely close." Karen Ashforth, OT MS CLT-LANA, June 2019, lymphaticnetwork.org



Over time, leaky veins increase microfiltration of lymphatic fluid



Increased localized inflammation



Buildup of fluid longstanding = chronic edema = lymphedema



Refer to CLT

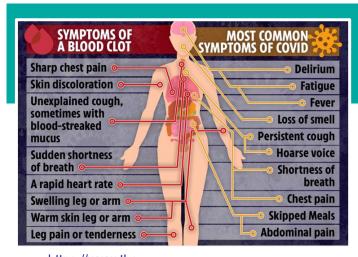


BLOOD CLOTS vs. COVID SYMPTOMS

Blood Clot Symptoms

Blood Clots/DVT: REFER TO ER

- Sharp chest pain usually worse
- with deep breath, coughing
- Skin discoloration
- Unexplained cough, blood in spittle
- Sudden shortness of breath
- Rapid HR
- Swelling in limb
- Warmth in limb
- Limb pain or tenderness
- Anxiety/Nervousness*
- Lightheadedness/blacking out*



https://www.the-sun.com/news/1980918/deadly-blood-clots-being-mistaken-for-covid/

Vanessa Chalmers, Digital Health Reporter, The U.S. Sun (online newspaper) 10:23 ET, Dec 16 2020 Updated: 3:34 ET. Dec 17 2020

COVID

Symptoms

COVID:

- Delirium
- Fatigue
- Fever
- Loss of smell
- Persistent cough
- Hoarse voice
- Shortness of breath
- Chest pain
- Loss of appetite
- Abdominal pain____



Blood Clots/DVT:





Superficial clots: usually not dangerous unless developing infection.

May just look like a bruise, but may progress



DVT: can occur in deep veins in limbs or gut



Do not treat until evaluated and medically stabilized



Cellulitis



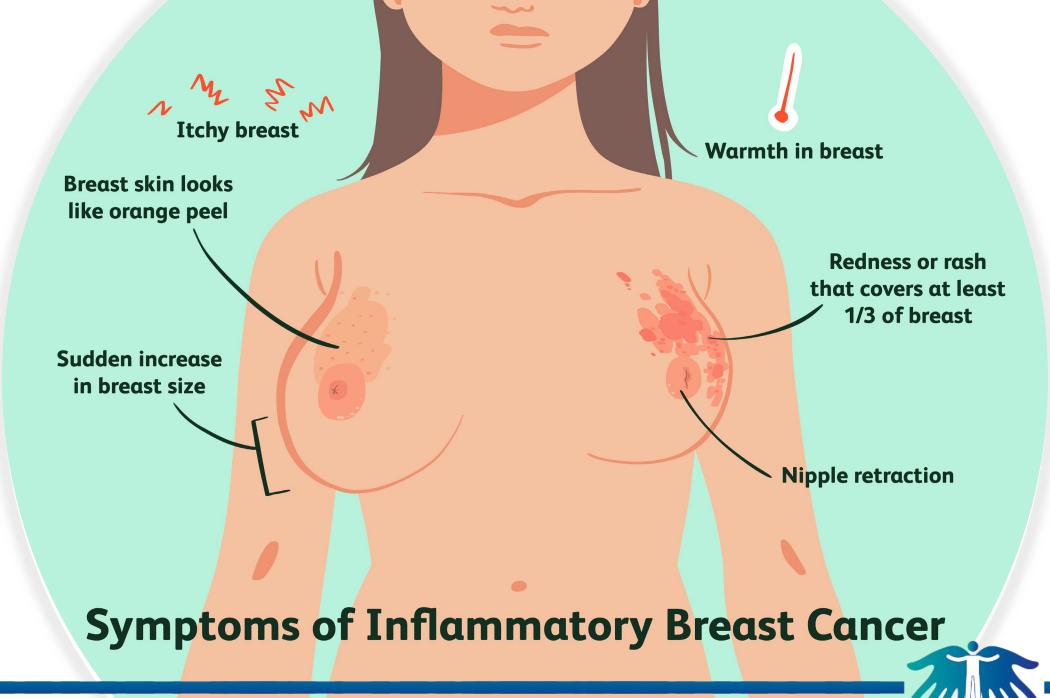


Cellulitis: REFER TO MD

- Bacterial skin infection
- Usually due to strep
- Signs and symptoms:
 - Red skin, map-like borders
 - Tenderness to touch/local pain
 - Warm or hot skin
 - Fever, nausea, headache
 - Fast progressing
 - Can be life threatening, lead to sepsis
 - Treated with antibiotics
 - High risk when lymph system
 - is damaged







Inflammatory Breast Cancer Refer to MD



IBC Per cancer.gov:
"a rare and very
aggressive disease in
which cancer cells
block lymph vessels in
the skin of the breast."





Signs & Symptoms

- Redness, or other discoloration (bruising) of breast
- Swelling of breast
- Rash-like appearance

- Peau d' orange
- May be noted on chest, proximal UE
- Indications for MLD, other treatment?



Polls



Lymphatic Therapy Resources

"The Big Seven"
A Sampling of Information from:
Websites
Social Media
Nonprofits
Manufacturers
Support Groups
Videos, Online Articles & Podcasts
Books



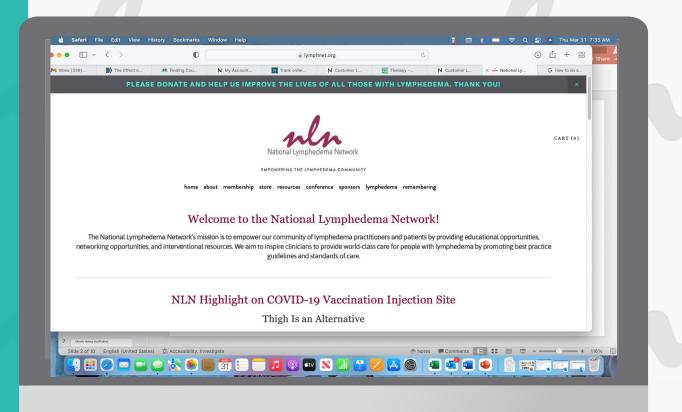


Our First Group - Websites

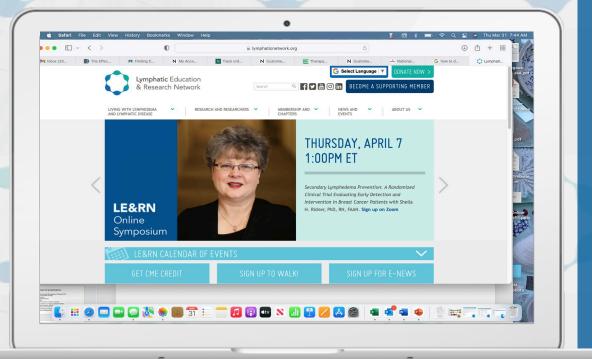
National Lymphedema Network (NLN)

https://lymphnet.org

NLN is 501(c)(3) nonprofit organization founded in 1988 to provide education and guidance regarding lymphedema management to patients, healthcare professionals, and the general public.









Lymphatic Education & Research Network (LE&RN) https://lymphaticnetwork.org

The Lymphatic Education & Research Network is an internationally recognized nonprofit organization founded in 1998 to fight lymphatic diseases (LD), such as lymphedema (LE), lipedema (LI), and lymphatic malformation (LM), through education, research and advocacy.



The Lymphedema Treatment Act (LTA) https://lymphedematreatmentact.org

The 3-5 million men, women and children living with lymphedema in the US must have insurance coverage for their medically necessary compression supplies.

The Lymphedema Treatment Act is a federal bill that would amend title XVIII of the Social Security Act and would provide for coverage of certain lymphedema compression treatment items under the Medicare program.

"Make Your Voice Heard" by contacting your members of Congress and asking them to support this important bill.



Our Second Group SOCIAL MEDIA



Lymphedema Therapists Helping Lymphedema Therapists

This private group is exclusive to therapists practicing lymphedema, not patients or vendors. One must receive an invite to be part of this group.



The Lymphie Life

began as a personal blog to connect with other lymphedema patients. It has evolved to educate, connect and support lymphedema patients and advocates across the globe. Check out this public group for tips and tricks, research news, product reviews, and interviews and more.



Lymphedema Diary

created by Britta Dornan on the 15th anniversary of the full onset of her primary lymphedema, is a public group where Britta shares her experiences hoping that she can help others who are living with lymphedema every day.



The Lipedema Society

established in 2001, they encourage advocacy, awareness, education & support for those affected by lipedema. A public Facebook group, The Lipedema Society is a medical resource & network for surgeons, healthcare workers, & women with lipedema.

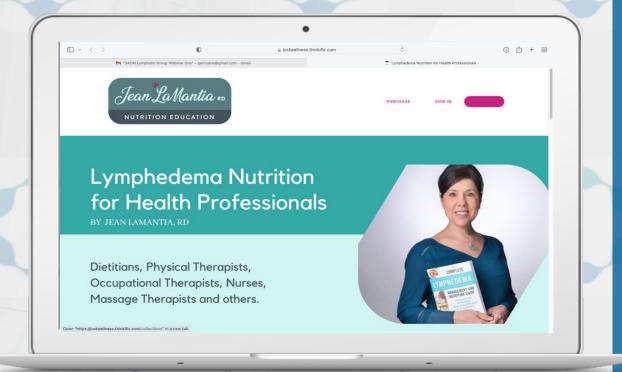


Lymphie Strong

is a global fitness group for people living with lymphedema by people living with lymphedema. This private Facebook group, the Lymphie Strong Running & Fitness Club for Lymphedema, shares exercise tips, successes, questions, and motivation to help those who are experiencing lymphedema.







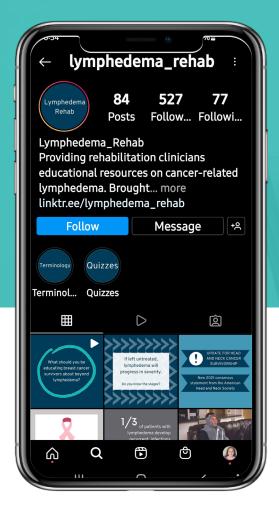


An Example of Information Shared in a Facebook Group: Jean LaMantia RD Nutrition Education

https://justwellness.thinkific.com/courses/lymphedema
-nutrition-for-healthprofessionals?fbclid=IwAR1Sre4ndIM8PzcpyRLJRpEwpvi
U2Qm ygS9aAPityl21h4GlvpbxoTfBmc

Jean LaMantia, a registered dietitian, author, speaker and presenter, is the creator of Lymphedema Nutrition School that helps people with lymphedema to learn about nutrition and improve their condition. The fees for each course that she offers is posted on her site.

INSTAGRAM





@lymphedema_rehab

Tactile Medical provides rehabilitation clinicians educational resources on cancer-related lymphedema. Contains quizzes and terminology for anyone to use in addition to links for PubMed articles.

https://www.instagram.com/lymphedema_rehab/?hl=en

@yacancerconnection

Social support and resources for young adults affected by cancer. Topics include: peer support & social networks, fertility, retreats, body images and financial assistance. https://instagram.com/yacancerconnection/







Other Forms of Social Media

Used in an informative and professional way, social media content and posts can increase one's client base and enable therapists to network and share ideas with one another.

Our Third Group — Nonprofit Organizations



https://imermanangels.org

Imerman Angels, created in 2006 by Jonny Imerman, on the belief that no one should have to face cancer alone and without the necessary support. Imerman Angels partners anyone, any age, any gender, anywhere and any cancer type seeking support with someone just like them — a "Mentor Angel," who is a cancer survivor or caregiver and has faced the same type of cancer.



https://4thangel.ccf.org

After recovering from cancer, Olympic gold medalist Scott Hamilton identified three angels who helped him: his oncologist at Cleveland Clinic, his oncology nurse and his family and friends. What he felt was missing was a fourth angel: someone who had been there and would understand what he was feeling. This led to a new program at the Cleveland Clinic in which cancer survivors and patients could talk to their peers about the cancer experience, bringing about the survivor-to-patient/caregiver mentoring programs.



Ninjas Fighting Lymphedema

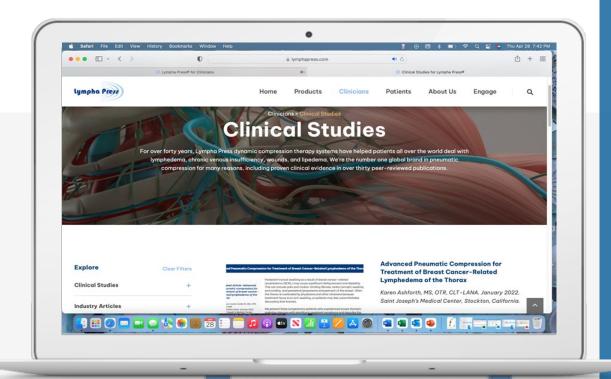
https://www.winourfight.org/our-story

Amy Rivera was born with primary lymphedema; however she was misdiagnosed for over 30 years, leaving her disabled and isolated. She established the Ninjas Fighting Lymphedema Foundation (NFLF) in 2017 to build relationships within the lymphedema community. Since then, they have raised over \$160,000, supported over 300 lymphedema thrivers across 23 countries and sponsored educational scholarships to certify four new lymphedema therapists.











Lympha Press

https://lymphapress.com

For over 40 years, Lympha Press has produced compression therapy products and helped patients all over the world with lymphedema, lipedema, chronic venous insufficiency, peripheral arterial disease (PAD) or wounds manage their condition and improve their quality of life. They have worked with VA Hospitals around the nation and veterans surveyed were prescribed the Lympha Press for their upper or lower extremity lymphatic conditions.

Lympha Press also contains an education section that contains excellent YouTube video/webinars for clinicians along with clinical studies which include proven clinical evidence in over thirty-peer reviewed publications.

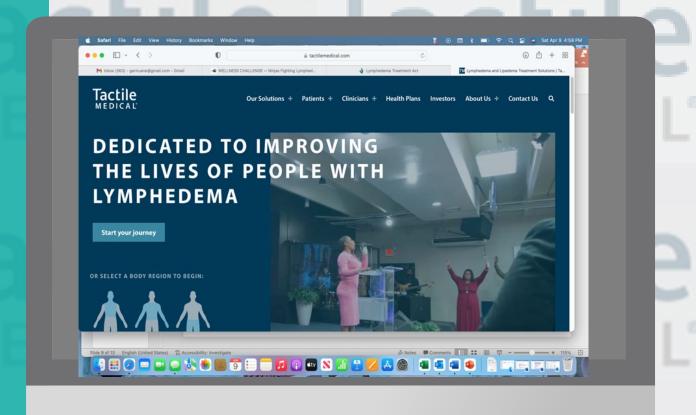
https://lymphapress.com/clinicians/#education





Tactile Medical http://tactilemedical.com

Tactile Systems Technology, Inc. is a medical technology company that is focused on developing medical devices (such as the Flexitouch) for the treatment of patients with underserved chronic diseases at home, such as chronic venous insufficiency (CVI). The Flexitouch system has been shown to reduce healthcare costs, stimulate lymphatic function, and significantly reduce edema and limb volume.

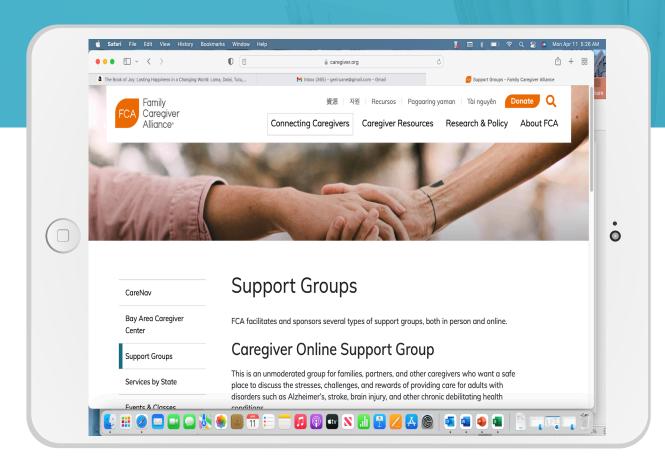




Our fifth group offers support for Healthcare Practitioners, Caregivers and Friends

Family Caregiver Alliance

https://www.caregiver.org/connecting-caregivers/support-groups/



A 2020 National Alliance for Caregiving (NAC) and AARP report also revealed that caregivers health has worsened since 2015. This is an unmoderated online group for families, partners, and other caregivers who want a safe place to discuss the stresses, challenges, and rewards of providing care for adults with disorders such as Alzheimer's, stroke, brain injury, and other chronic debilitating health conditions.

Lymphology Association of North America (LANA)—

a resource for patients, caregivers, therapists and practitioners

https://clt-lana.org/public

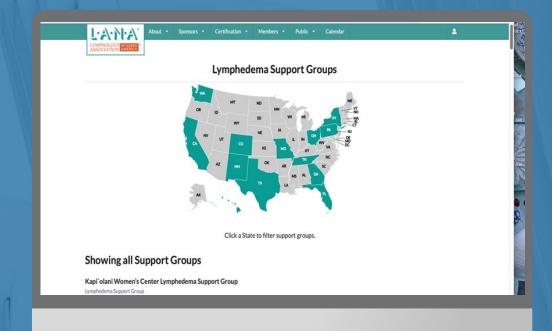
Lymphedema Support Groups

click on a state in the map to filter the support groups

https://clt-lana.org/support

Resource Links

this section contains a listing of national/international support groups regarding all lymphatic health issues https://clt-lana.org/resources-links



Public Webpage

check out their "public" section of the LANA website for a wealth of information.

https://clt-lana.org/public





Educational YouTube videos about our lymphatic system:



"The Lymphatic System" — approximately 29 minutes in length

https://www.youtube.com/watch?v
=P8jAtFxMKcA



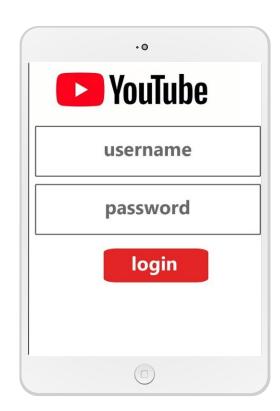
"Fuse School – The Lymphatic System" — approximately 4 minutes in length

https://www.youtube.com/watch?v=o0-10knb03M



Khan Academy India-Lymph System — approximately 14 minutes in length

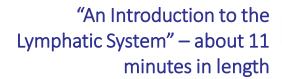
https://www.youtube.com/watch?v=o TVdv
aMCWA



"Professor Dave Explains" – about 15 minutes in length



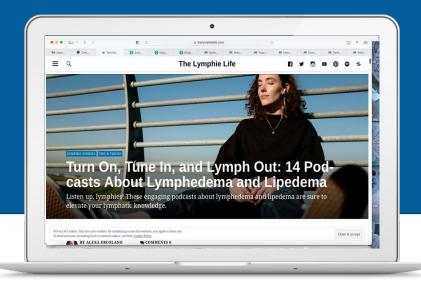
https://www.youtube.com/watch?v =DZX5AGST8gE





https://www.youtube.com/watch?v =QD9AdNXSQe4



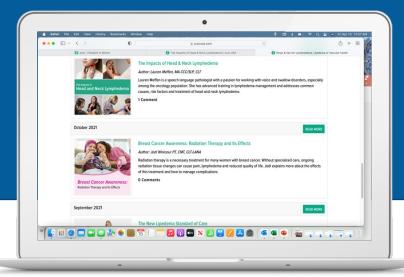




The Lymphie Life - Podcasts

https://thelymphielife.com

"Turn On, Tune In, and Lymph Out: 14 Podcasts about Lymphedema and Lipedema"





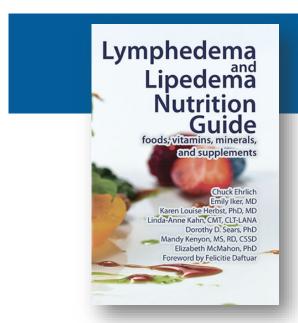
"Steps to Better Health" Monthly Online Articles

https://www.juzousa.com/Juzo-Blog



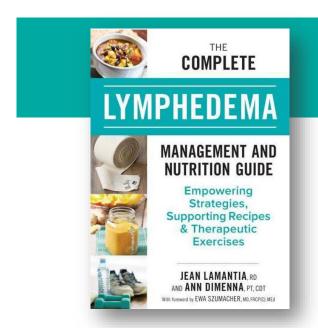


Books



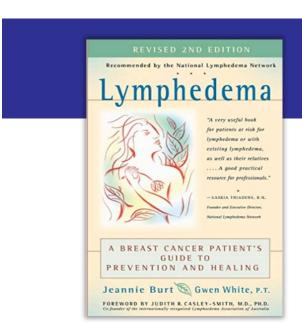
Lymphedema and Lipedema Nutrition Guide: Foods, Vitamins, Minerals and Supplements

> By Chuck Ehrlich, Emily Iker, Karen Louise Herbst, et al



Complete Lymphedema
Management and Nutrition Guide:
Empowering Strategies, Supporting
Recipes and Therapeutic Exercises

By Jean LaMantia, Ann DiMenna

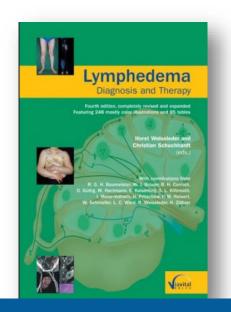


Lymphedema: A Breast Cancer Patient's Guide to Prevention and Healing

By Jeannie Burt and Gwen White, P.T.

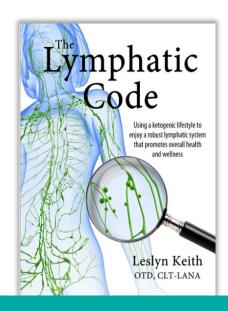


Books (cont.)



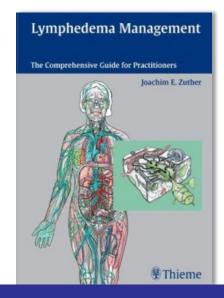
Lymphedema:
Diagnosis and Therapy
(fourth edition, completely
revised and expanded)

By Horst Weissleder and Christian Schuchhardt



The Lymphatic Code

By Leslyn Keith, OTD, OTR/L,CLT-LANA



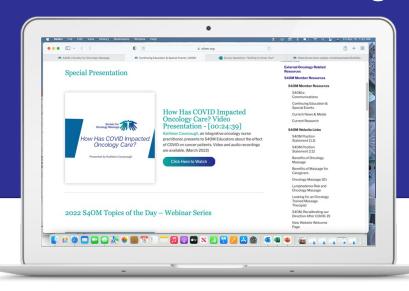
Lymphedema
Management: The
Comprehensive Guide for
Practitioners 4th Edition

By Joachim Ernst Zuther and Steve Norton



Society for Oncology Massage

S4OM.org – take a look and learn more!





- Topics of the Day
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- •Find a Course or Training Schedule
- Community Resources
- Continuing Education

Questions?

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Past Webinars & Special Presentations

Click <u>here</u> to access recordings

TOPICS OF THE DAY SERIES



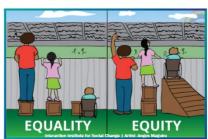
'Our COVID-19 Stories'



TOPICS OF THE DAY SERIES

"Health Equity: Awareness into Action - Part 1"





Our COVID Stories (No CE's available)

In 2021 S4OM introduced Topics of the Day with a panel discussion on the impacts and realities of COVID19 in a variety of oncology massage practice settings. Many participants provided feedback that it helped them feel less alone in the problems they were facing.

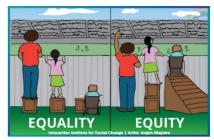
Health Equity: Awareness into Action – Part 1 (1.5 CE)

This presentation was designed to help S4OM members better understand the concept, improve awareness of the factors that contribute to health equity, and to recognize areas where there are opportunities to improve health equity in the massage industry.

TOPICS OF THE DAY SERIES

"Health Equity: Awareness into Action — Part 2"





How Has COVID Impacted Oncology Care?

Presented by Kathleen Cavanaugh

Health Equity: Awareness into Action – Part 2 (1.5 CE)

This presentation provides a chance to learn more about recognizing and responding to the moments we are given to improve health equity for oncology patients in different practice settings. It also includes time to brainstorm with colleagues on how to begin taking action to address these opportunities.

How Has COVID Impacted Oncology Care? Video Presentation

Kathleen Cavanaugh, an integrative oncology nurse practitioner, presents to S4OM Educators about the effect of COVID on cancer patients. Video and audio recordings are available.

