



Lymphedema 20/20

The State of CDT and the Treatment of Lymphedema and Lipedema

Gunter Klose, CLT-LANA
MLD/CDT Cert. Instructor




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What's Ahead

1. Lymphedema Precautions/Risk Reduction Practices
2. Modern MLD or no MLD – Is it time to change old practice?
3. Providing effective CDT
4. Taking a new look at Lipedema
5. Starling's Law – Its revision and the glycocalyx; A new look at the fluid dynamics on the capillary wall



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Juzo Power 2020

Gunter's Presentation
Lymphedema 20/20: Lymphedema and Lipedema Treatment Updates

KLC 2019: Linda Hodgkins



Lymphedema Precautions / Risk Reduction
Debunking Lymphedema Risk-Reduction Behaviors: Risky Conclusions. J. Nudelmann. *Lymphatic Research and Biology*, 14(3): 124-126, 2016. (Editorial)

Impact of Ipsilateral Blood Draws, Injections, Blood Pressure Measurements, and Air Travel on the Risk of Lymphedema for Patients Treated for Breast Cancer: C. Ferguson, et al. *Journal of Clinical Oncology*, 34(7): 691, March 1, 2016.



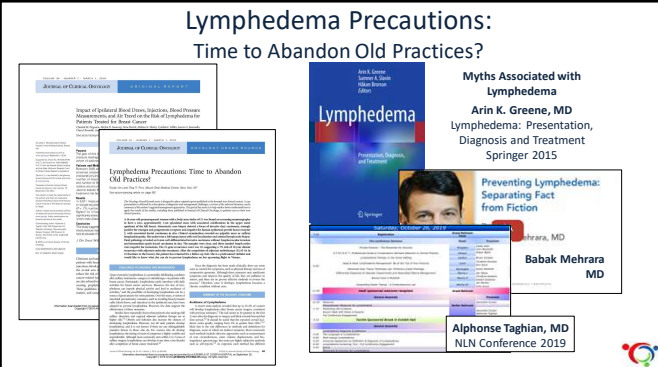
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Lymphedema Precautions

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Lymphedema Precautions: Time to Abandon Old Practices?




Myths Associated with Lymphedema
Arin K. Greene, MD
Lymphedema: Presentation, Diagnosis and Treatment
Springer 2015

Preventing Lymphedema: Separating Fact from Fiction
Mehra, MD

Babak Mehrara MD

Alphonse Taghian, MD
NLN Conference 2019



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LYMPHATIC RESEARCH AND BIOLOGY
Volume 14, Number 3, 2016
© Mary Ann Liebert, Inc.
DOI: 10.1089/lrb.2016.0027

Debunking Lymphedema Risk-Reduction Behaviors: Risky Conclusions


Judith Nudelmann, MD

Guest Editorial

A RECENT ARTICLE in the *Journal of Clinical Oncology* by Ferguson et al.¹ is being summarized, both in the *NEJM Journal Watch* and in the associated JCO editorial by Ahn and Port,² as demonstrating and proving that iatrogenic trauma to the at-risk arm and flying without compression garments do not cause breast cancer-related lymphedema (BCRL), and clinical practice should be changed to reflect these conclusions. *Journal Watch* states: "Study debunks conventional guidance about lymphedema prevention."

A physician or health care provider can now rebuke a woman who asks for avoidance of an IV/automatic blood pressure measurement/M injection that the evidence "proves" she is at no risk. The editorial states that only weight gain and infection are proven to cause BCRL, and counsels providers to take blood swelling in the hand or chest. It cannot measure subclinical lymphedema without measurable swelling. It is not a stand-alone tool for measuring lymphedema and cannot ascertain volume increases in the entire quadrant at risk. Lymphedema is not a static disease, and those women with fluctuating swelling and swelling in the hands, trunks, or breasts will be missed by the perimeter. The greatest yield in diagnosis comes from careful observation, surveys, and volume measurement.³ The editorial dismissed surveys as subjective, yet Armer et al. and others have found surveys to be both validated and highly correlated with BCRL.

Ferguson et al. presented an observational study, which has limitations. The patients' arm volumes were used to determine whether they had lymphedema. The authors were careful to state




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Painful lymphedema afflicts millions of patients after cancer surgery
 By Renee Blangit
 Special to The Washington Post
 Monday, November 2, 2016, 2:40 PM

It's the aftermath of cancer surgery, a complication that breast cancer survivors [Bianca and Phoenix](#) call "cancer treatment's dirty little secret," a nasty surprise that ends up on you.

Special garments ease an agonizing ailment for women. But insurance may not pay.


By Carmen Hernandez Rodriguez



Yes, breast cancer survivors, you can lift weights, get manicures and garden

By Susan Berger
 July 6, 2019 at 10:30 a.m. MDT




For more than 25 years, many breast cancer survivors were given a lifelong, life-changing warning: Do not lift anything over five pounds, avoid getting manicures, taking saunas or even gardening since it might lead to a painful complication called lymphedema, which can cause irreversible swelling in the arm and often hardening of skin.




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Take Home Message


- Risk Reduction Practices are not obsolete!
- Education is power!


NLN's Risk Reduction Practices
 NLN's Healthy Habits chart
lymphnet.org/position-papers



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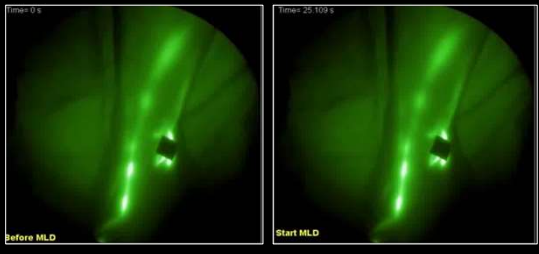


**Modern MLD or no MLD:
 Is it time to change old practice?**



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NEAR-INFRARED FLUORESCENCE IMAGING



Before MLD During MLD

E.M. Speck-Munoz

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There is no universal agreement about the correct technique of MLD!

Chickly
Casley-Smith
Vodder
Leduc
Modern MLD

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The quality of MLD varies a great deal from one practitioner to the next:

- Training received
- Therapist passion/enthusiasm
- Time constraints
- Reimbursement issues
- Productivity pressure
- Scheduling issues

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The Role of ICG Fluorescence Lymphography in MLD

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TECHNICAL ADVANCE Open Access

A new indocyanine green fluorescence lymphography protocol for identification of the lymphatic drainage pathway for patients with breast cancer-related lymphoedema

Hiroo Suami^{1*}, Asha Heydon-White², Helen Mackie^{1,3}, Sharon Carmac⁴, Louise Koelmeyer¹ and John Boyages¹

Comparison of ICG lymphography, tracing photo and lymphoscintigraphy in the same patient

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Patterns of drainage pathways in ICG lymphography images (left) and tracing photos (right): A: ipsilateral axilla, B: clavicular, C: parasternal, and D: contralateral axilla

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Development of ICG Lymphography Staging

Indocyanine green lymphography staging scale

Stage	0	1	2	3	4	5
Patent lymphatic vessels	+++	+++	++	+	0	0
Dermal backflow	0	+	++	+++	++++	0
Lymphatic vessel contractility	+++	+++	++	++	+	0

Chang DW, Suami H, Skoracki R. *Plast. Reconstructive Surgery*, 2013
 Nguyen AT, Suami H, et al. *Journal of Surgical Oncology*, 2016

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Breast cancer (N=103)

LYMPHATIC DRAINAGE REGIONS

MDA stage	No.	ICG drainage regions				
		Ipsilateral axilla	Clavicular	Parasternal	Contralateral axilla	Ipsilateral inguinal
1	19	95%	21%	5%	0%	0%
2	46	61%	52%	7%	2%	0%
3	20	70%	55%	5%	5%	0%
4	18	50%	17%	17%	17%	0%
Total	103	67%	41%	8%	5%	0%

Unspecified: 2 cases in stage 4

Hiroo Suami, MD – Harvard Symposium 2018

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Breast cancer (N=103)

LYMPHATIC DRAINAGE REGIONS

Axillary surgery:

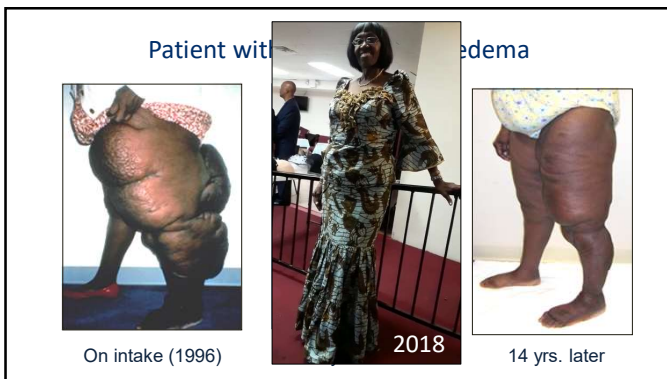
- Axillary dissection: 99
- Sentinel node biopsy: 2
- Unknown: 2

Hiroo Suami, MD
Harvard Symposium 2018

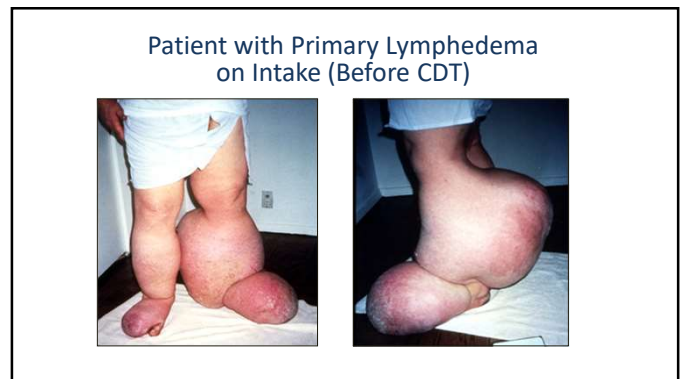
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ICG-Guided MLD

Data presented at the 2019 KLC, Denver

- 67% of women after axillary dissection still drain to the ipsilateral axilla.
- MLD may be performed more gently and faster in case of patent lymph vessels/drainage.
- MLD should be performed more firmly and slower in areas of dermal backflow.

Louise Koelmeyer, BAppSc (OT)
ALA Accredited Practitioner

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INTERNATIONAL CONSENSUS

BEST PRACTICE FOR THE MANAGEMENT OF LYMPHOEDEMA

...there is no doubt that they (MLD & SLD) are of immense value in providing psychological and symptomatic benefits.

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MLD alone is **NOT** the treatment for lymphedema!

Patient has been treated with MLD for 10 years

After 3 weeks of CDT (4x/week)

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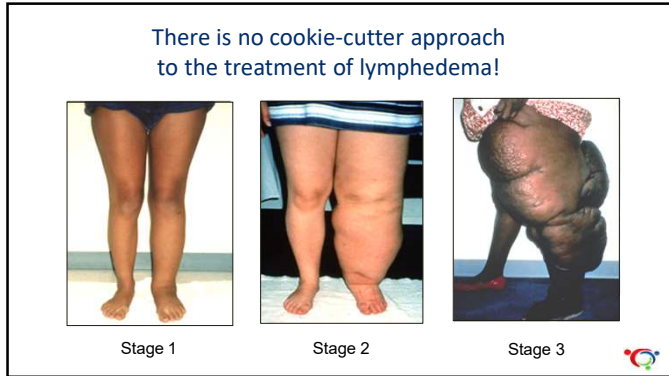
Take Home Message

- MLD treatment needs to be tailored to each patient's needs.
- Don't shortchange your patients by offering inadequate MLD therapy.
- MLD is, and must remain an integral part of CDT.

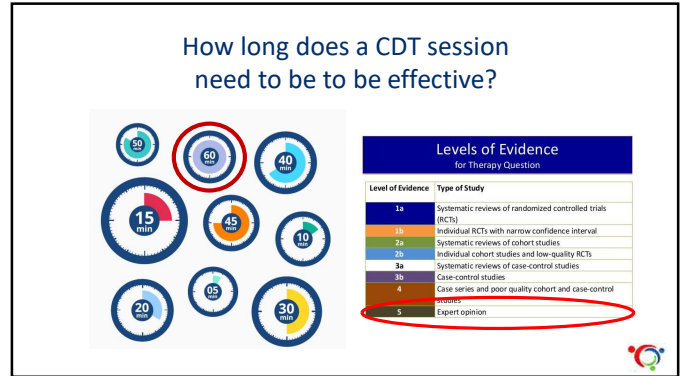
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Effective CDT The Inconvenient Truth

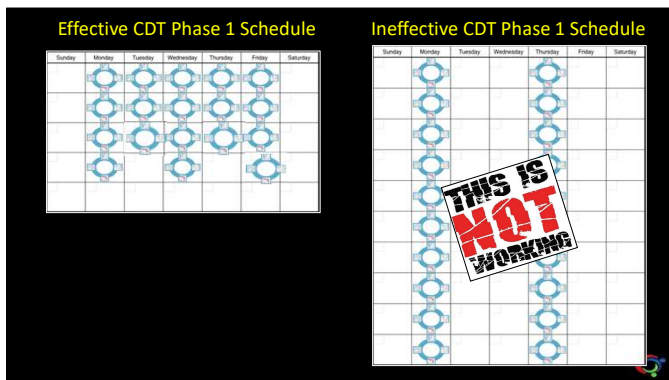
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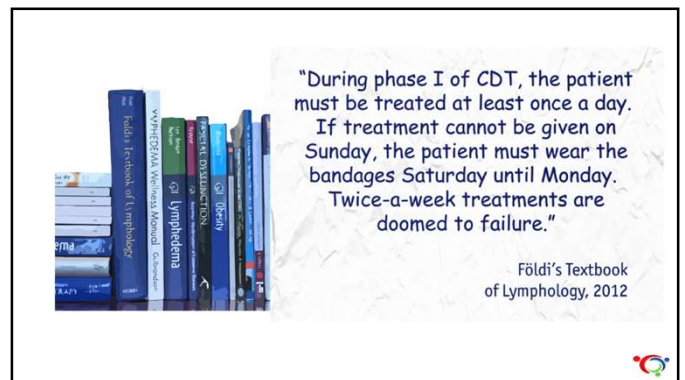
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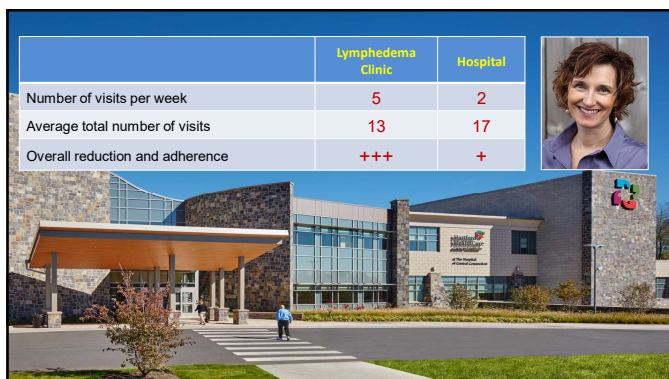
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So, what about:




- My patients don't want to come 5x/week...
- It's not practical for them...
- My Patients don't want to be bandaged...
- My patients can't afford _____.



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Take Home Messages

- To provide effective Phase 1 CDT, patients need to be treated 4-5x/week for 60min each session.
- Patients need to be educated to NOT accept substandard/inadequate CDT!

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Taking a New Look at Lipedema





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Classic Description of Lipedema





- Symmetrical adipose tissue deposition (swelling) of both lower extremities
- Affects mainly women
- Hypersensitivity of the increased subcutaneous tissue
- Develops hematomas very easily
- Adipose tissue is resistant to diet and exercise
- Knee pain is a feature of lipedema
- Orthostatic edema
- May turn into lipo-lymphedema
- Onset during puberty, sometimes after pregnancy



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Stages of Lipedema

Stage I	Skin surface normal, nodular (small) fatty tissue structure
Stage II	Skin surface uneven (peau d'orange), nodular (big) fatty tissue structure
Stage III	Lobular deformation due to increase in fatty tissue (Child 2010)

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What is lipedema?

The disease they call "FAT,"

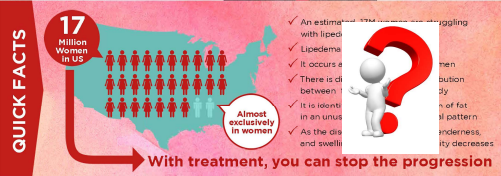

It's not your fault. It's not because of how much you're eating or how much you're exercising. Lipedema is a medical condition that millions of women have inherited.

"Finding out I have lipedema was more of a relief, it wasn't a scary thing at all. I knew what I had and all I had to do was figure out how to live with it."
- Nicole, Stage 2 Lipedema

QUICK FACTS

- 17 Million Women in US
- An estimated 11% of women are struggling with lipedema
- Lipedema is a chronic condition
- It occurs in both men and women
- There is a difference between lipedema and obesity
- It is associated with insulin resistance
- As the disease progresses, the skin thickens and swells
- Almost exclusively in women

With treatment, you can stop the progression

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Lipedema or Lipohypertrophy?

STAGE 1
Skin looks normal, but a spongy consistency is felt when touched.

STAGE 3
Fat deposits on the legs are bulky, hanging over the hips, knees, and ankles. Legs feel stiff and fat beneath the skin feels harder and more fibrous.

STAGE 2
Large fat deposits with indentations begin to form on the legs, especially around the knees and ankles.

STAGE 4
Fat deposits are so large and extreme that the entire lymph system is affected, leading to severe swelling, protruding growths, and even leaking from the skin.

“The journey to get a diagnosis was frustrating and demeaning. I was blamed and shamed and made to feel I was cheating and that the weight was my own fault.”

The Friedman Center for Lymphedema Research and Treatment at Northwell Health

The Lipedema Project
The Disease They Call FAT documentary available [DiseaseTheyCallFAT.tv](#)

the **lipedema** project
THE DISEASE THEY CALL FAT

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Lipedema or Lipohypertrophy?

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Albert Einstein

Lipedema is a very complex condition!

- 1) Physical
- 2) Psychological
- 3) Emotional
- 4) Psycho-Social
- 5) Spiritual
- 6) Cultural

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Lipedema – myth

T Bertsch, G. Erbacher

Lipedema – myths and facts Part 5

T Bertsch, G. Erbacher

Lipedema – myth

T Bertsch, G. Erbacher

Lipedema – myths and facts, Part 5*

European Best Practice of Lipedema – Summary of the European Lipedema Forum conference

Lipödem – Mythen und Fakten Teil 5

Spezialkongress Europäische Best Practice of Lipedema – Zusammenfassung des Kongresses des Europäischen Lipödem Forum

**Tobias Bertsch, MD & Gabriele Erbacher, Clinical Psychologist
Foeldi Clinic, Hinterzarten, Germany**

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Lipedema – Myths and Facts, Part 5

The term Lipedema is misleading and incorrect!

*There is **no** scientific evidence that...*

- lipedema is an “edema problem”.
- MLD can reduce the patients’ complaints because of its “drainage” effects.
- lipedema is a progressive disease.
- weight loss is not effective.
- lipedema causes lymphedema.
- 11% of the female population suffer from lipedema, or that the onset of lipedema is during puberty.

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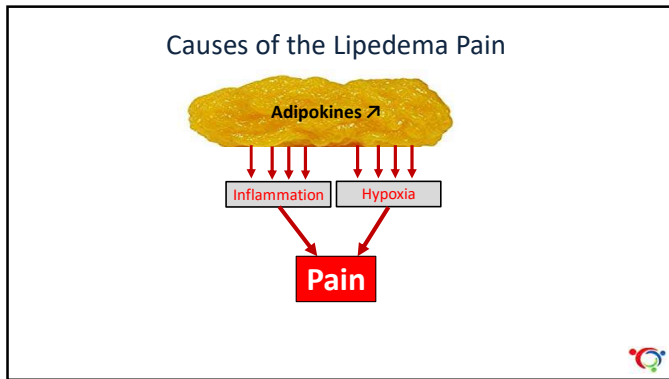
Lipedema is **not** an “edema problem”

Patient with lymphedema of the distal lower leg and forefoot and lipedema restricted to the thigh and proximal lower leg

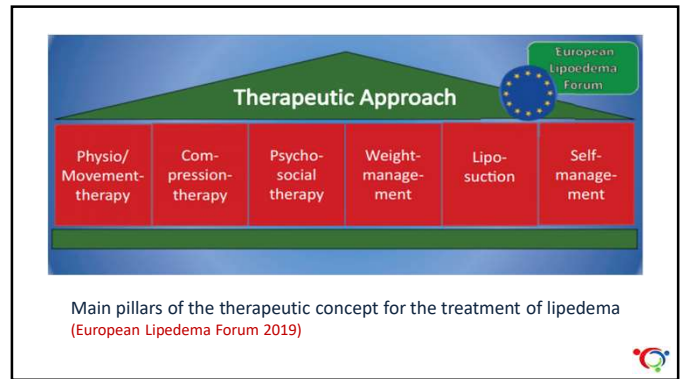
Proximal thigh of the patient with typical ultrasound image of lipedema with unremarkable dermis, thickened subcutaneous tissue, and no evidence of fluid in the soft tissues

Distal right leg of same patient with typical ultrasound image of stage 2 lymphedema with partial separation of soft tissues, thickened subcutaneous tissue and fluid in the tissues (small arrows)

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MLD or no MLD?
 Reduce edema – No
 Improve subjective complaints – Yes

How about compression therapy?
 Reduce edema – No
 Decrease inflammation – Yes
 Improve microcirculation (hypoxia) – Yes
 Decrease subcutaneous pain – Yes
 Night compression – No

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MLD or no MLD?
 Reduce edema – No
 Improve subjective complaints – Yes

How about compression therapy?
 Reduce edema – No
 Decrease inflammation – Yes
 Improve microcirculation (hypoxia) – Yes
 Decrease subcutaneous pain – Yes
 Night compression – No

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“Compression therapy has always been and still is an important element of Best Practice in the treatment of patients with lipedema!”

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MLD or no MLD?
 Reduce **lymphedema** – Yes
 Improve tissue health – Yes

How about compression therapy?
 Reduce **lymphedema** – Yes
 decrease inflammation – Yes
 Improve microcirculation (hypoxia) – Yes
 Decrease subcutaneous pain – Yes
 Night compression – lower leg to knee

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Figure 6. STAGE III LIPEDEMA WITH LARGE DEFORMING FAT DEPOSITS. NOTE SIZE DIFFERENCE BETWEEN UPPER AND LOWER BODY

How about MLD and Compression?




Reduce lymphedema

Yes, but in the context of a multimodal (multidisciplinary) approach

Night compression

Chronic pain


YES



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Obesity and Lipedema


Obesity is Multi-Factorial




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Obesity and Lipedema

- 80-88% of lipedema patients are obese.
- Being overweight or obese is an aggravating factor of lipedema.
- Majority of patients tried “diet and exercise” and experience a yo-yo effect.
- With lipedema, the advice to lose weight conventionally is particularly pernicious. **95%** of all people who lose weight with the usual conventional diets regain the weight within 3 years.



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- Women (in contrast to men) regain a disproportionate amount of weight in the lower body after weight loss. In other words: every medical recommendation to a lipedema patient to lose weight increases the risk of exacerbating the lipedema.
- Obese patients with lipedema often experience a lack of fitness and mobility
- Lipedema is not usually a progressive disorder! Instead, patients with lipedema experience weight gain (obesity) which can lead to exacerbation of the lipedema.
- Obesity/weight gain must addressed!



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Weight loss is ~~X~~effective



Lipedema patient (269 lbs., 168 cm, BMI 43) before sleeve gastrectomy.

Same patient 11 months after bariatric surgery. Weight now 163 lbs., BMI 26.



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Weight loss is effective.



A: Patient with lipedema and predominately distal leg edema.

B: Same patient 1 year later, after a gastric bypass.

C: Excess skin with subcutaneous fat.



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Weight loss is effective.



At baseline

After losing 80lbs on Keto

After liposuction



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Weight Management

- Short-term diets must be avoided by all means.
- The concept of energy balance has to be taught.
- Patients must be educated about the inflammatory and anti-inflammatory effects of their dietary habits and food choices.
- To achieve long-term weight stabilization, support and coaching are necessary.



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Measures to Reduce Hyperinsulinemia

- Maintain sufficiently long intervals between meals (4-6 hrs. daytime and at least 12 hrs. nighttime).
- Strictly avoid constant “grazing” (especially sweets).
- Avoid foods containing refined carbohydrates or sugar.
- Eat “real” food instead of processed foods.
- Consume healthy fats and avoid industrial trans-fats.



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Stabilize and Exercise



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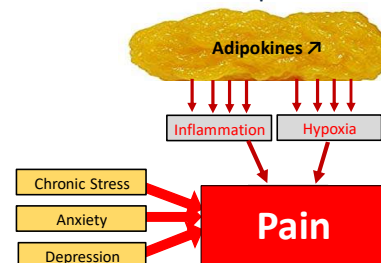
Psychology in Lipedema

- The impact of psychological stress in patients with lipedema is underestimated!
- Psychological vulnerability contributes to the amount of pain perception.



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Causes of the Lipedema Pain



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Psychology in Lipedema

- The impact of psychological stress in patients with lipedema is underestimated!
- Psychological vulnerability contributes to the amount of pain perception.
- Eating disorders are often present and need to be treated.
- Lack of self-acceptance because of current beauty ideal.
- **Psychological assessment is a must!**




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Liposuction

Not every patient with lipedema will benefit from liposuction!

Liposuction may be considered if:

- Symptoms persist despite at least 12 month of comprehensive conservative treatment, as presented above
- The patient has considerable functional disability
- The patient's weight has been stable for at least 12 months
- A preoperative psychological assessment is completed



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
Motivation is an essential ingredient for changing behavior.

Self-Management The "Math of Motivation"

The Motivational Matrix:
Motivation = importance¹ x self-efficacy²

Any amount of knowledge multiplied by zero motivation will not change a thing!	High importance of the goal X Low self-efficacy	High importance of the goal X High self-efficacy
	Low importance of the goal X Low self-efficacy	Low importance of the goal X High self-efficacy

¹ Importance of the goal
² The belief in one's own ability to achieve the goal



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MasterClass BEYOND LIPEDEMA

TRIBE

WASTOPPPABLE KETO Welcome


Lipedema Tribe Community

lipedema simplified




Members only


lipedema-simplified.org




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Knowledge is Powerful




Mentoring is Supportive



Community is Nurturing

Our Mentors are Here to Help



ADVISOR | FRIEND | TUTOR | TEACHER | COACH | GUIDE

Catherine Sax, PhD, Founder & Director, Lipedema Simplified

Brenda Gold, BHS, PT, Physiotherapist & Emotional Freedom Coach


Carol "Rosie" Rowensitt, PhD, RN, FNP, Obesity Treatment & Thyroid Specialist

Lailyn Walsh, OTS, CLT-LANA, Researcher, Lymphatic Instructor, Occupational Therapist

Megan Pfeiffer, BHS, Clinical & Therapeutic Nutritionist

Mende Stagg, BA, Keto Chef & Coach


Rosam Sparks, BEd, Keto & Mobility Coach




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Take Home Messages


- Lipedema is a complex condition.
- Lipedema is not an edema issue.
- Patients with lipedema should be treated in a multi-modal approach.
- Psychological evaluation and weight management must be discussed with each patient.
- Patients must take ownership of their condition/health.






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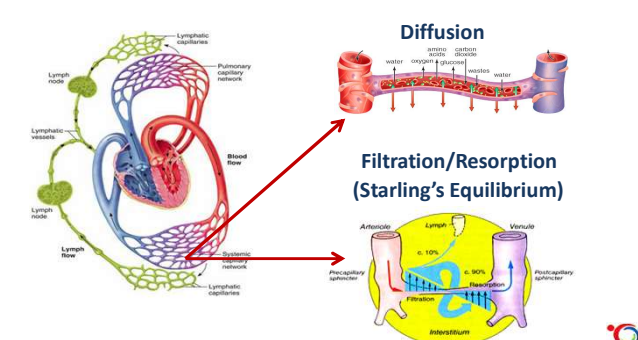
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Starling's Law – Its revision and the glycocalyx.
A new look at the fluid dynamics on the capillary wall.




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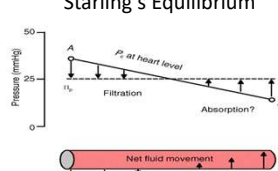
Diffusion

Filtration/Resorption (Starling's Equilibrium)



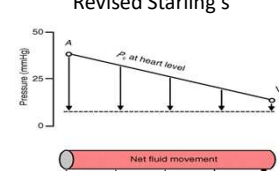
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Starling's Equilibrium




approx. 2-3 l/day

Revised Starling's




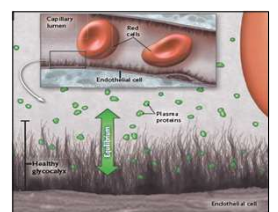
approx. 6-8 l/day

Levick J, Michel C. Microvascular fluid exchange and the revised Starling principle. *Cardiovascular Research*. 2010




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The Glycocalyx

Reitsma S, Slaaf D, Vink H, et al. "The endothelial glycocalyx: composition, functions and visualization" *Arch-Eur J Physiol* 2007

Mayburgh JA, Mythen MG. "Resuscitation Fluid" *N Engl J Med* 2013;369:13



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Ulises Baltazar
MD, FACS, CLT

Watch Dr. Baltazar's presentation at: klosetraining.com/juzopower2020




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Take Home Messages



- The glycocalyx is the gate keeper for fluid exchange/controls microcirculation.
- The glycocalyx is a highly complex structure that can be damaged by inflammation and poor nutrition.



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