EXCLUSIVE LIVE WEBINAR

Lipedema and Lymphedema - Two Conditions Dietitians Weren't Taught but Should Have Been

PRESENTED BY

Jean LaMantia RD

EARN
1.5 CEUs

June 28, 2023
2-3:30pm ET

Disclosures

- **Jean LaMantia** faculty for this educational event, has no relevant financial relationship(s) with ineligible companies to disclose
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This activity will also award credit for dietetics (CDR CPEU).

Learning Objectives

1. Explain the differences between lipedema, lymphedema, and obesity.
2. Discuss three nutrition strategies for lipedema and lymphedema.
3. Describe the role of a healthy lymphatic system.
4. Identify the risk factors for the development of lymphedema.
5. Illustrate the roles of an interprofessional team in treating lipedema and lymphedema.

Agenda

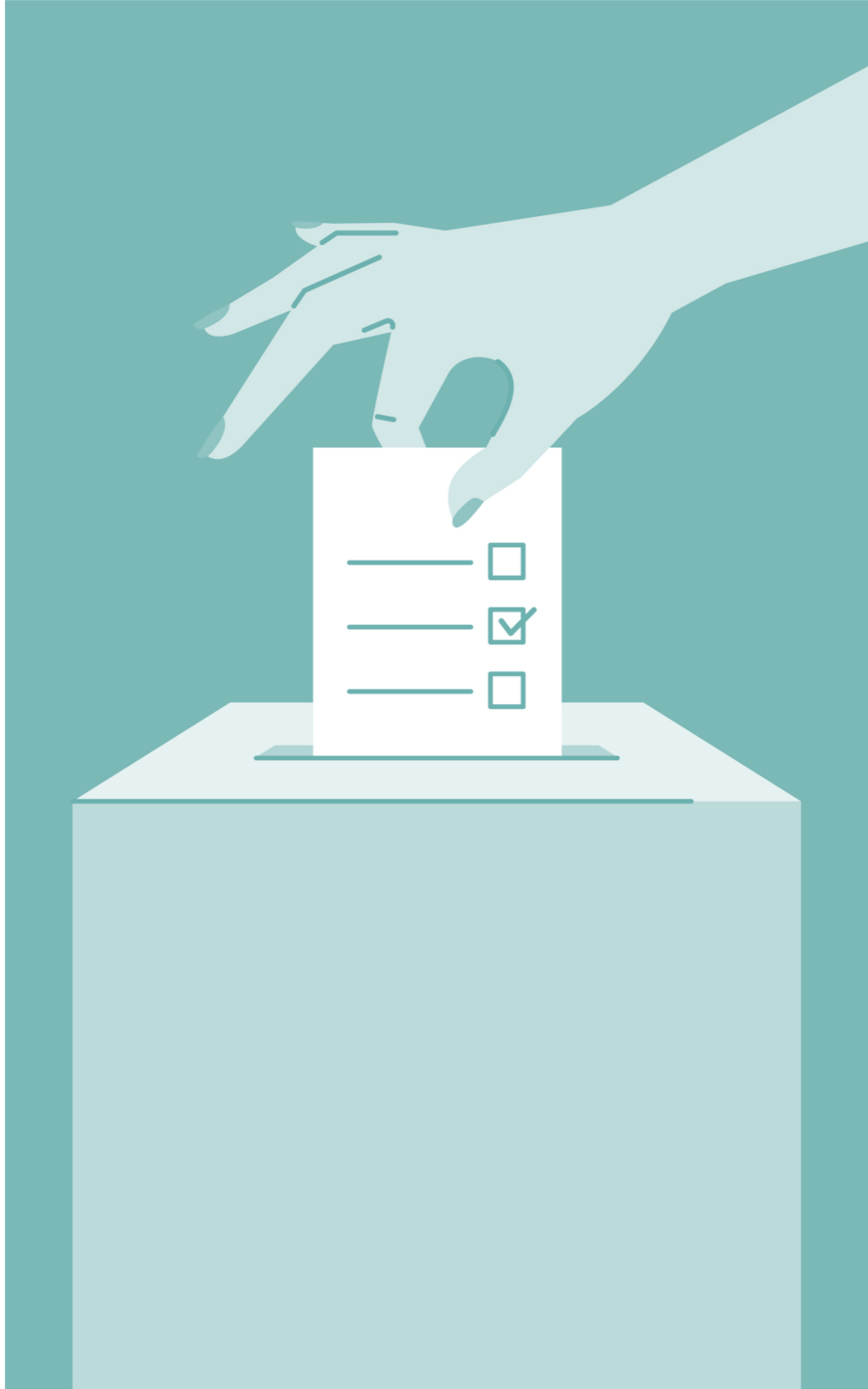
- An introduction to lymphedema and lipedema
- Key recognition and differentiation skills

  - Recognizing and diagnosing lymphedema
  - Lymphedema co-morbidities – obesity and cancer
  - Diet for lymphedema

  - Recognizing and diagnosing lipedema
  - Diet for lipedema

Poll Questions

1. Can you recognize lymphedema?
2. Can you recognize lipedema?
3. Do you know the difference between lipedema, lymphedema and obesity?



Diagnosing Lymphedema

Lymphedema and Lipedema

Lymphedema

Accumulation of protein rich lymphatic fluid

1

Lipedema

Uncontrolled growth of painful nodular fatty tissue. A connective tissue disease.

2

Photo source: 1. LaMantia, J, Dimenna, A. et al. (2019*) The complete lymphedema management and nutrition guide: empowering strategies, supporting recipes and therapeutic exercise.* Robert Rose.
2. National Health Services (England), https://www.nhs.uk/conditions/lipoedema/

Why Discuss Them Together?

Lymphedema

1

Lipedema

2

1. Treatment is similar/same
2. They can co-occur and later stages lipedema can cause lymphedema and later stage lymphedema can lead to lipedema-like fibrotic tissue

Photo source: 1. LaMantia, J, Dimenna, A. et al. (2019*) The complete lymphedema management and nutrition guide: empowering strategies, supporting recipes and therapeutic exercise.* Robert Rose.
2. National Health Services (England), https://www.nhs.uk/conditions/lipoedema/

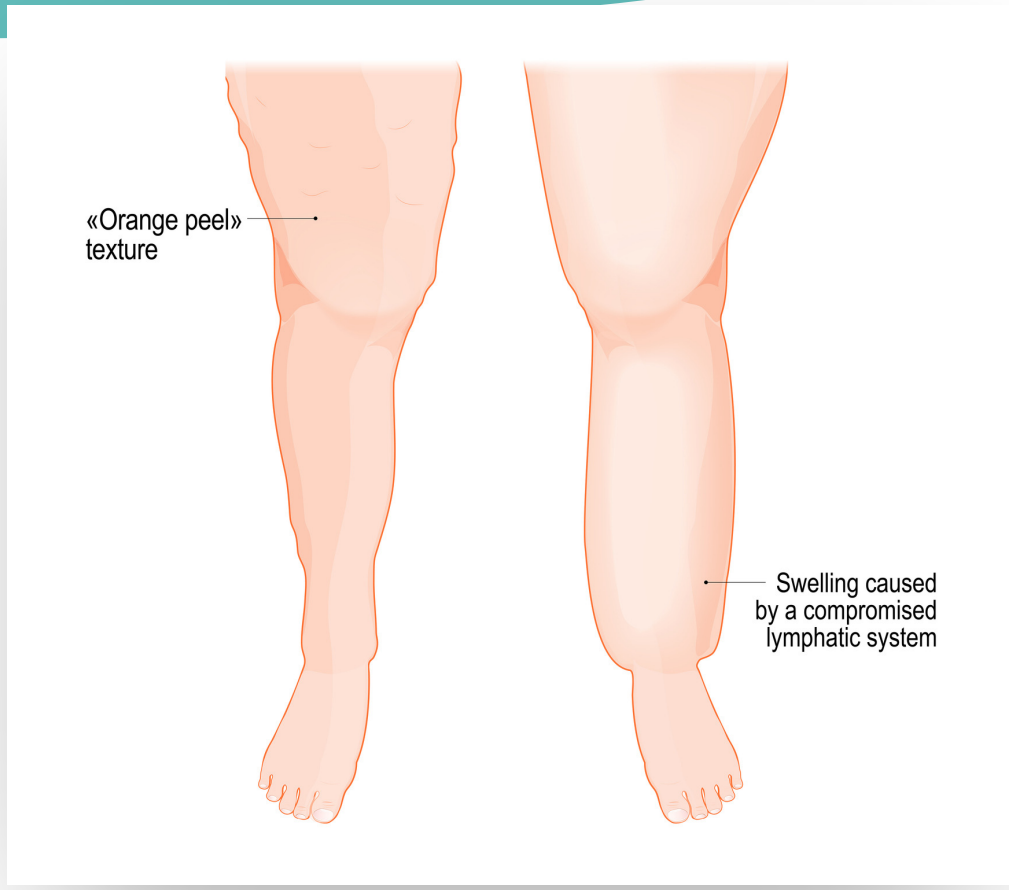
What Could the Swelling Be?

- Heart failure
- Renal failure
- Hypoproteinemia
- Pulmonary hypertension
- Peripheral vascular disease
- Lymphedema

Lymphedema, Lipedema, Lipo-lymphedema and Larger Body

Differentiation

- Hands and feet involved or not?
- Ankle/wrist cuff?
- Saddlebags/bat wings/gluteal shelf?
- Nodules present?
- Spongy skin?
- Symmetry vs. asymmetry?
- Pain?
- Abdominal involvement?
- Pitting edema?
- Comorbidities?



Schwartz J. All About Dercum's Diesase and Lipedema Patients. Total Lipedema Care dot com. Last Updated Nov 30, 2019. Accessed May 29, 2023.
Photo source: @dr.danielbenitti

Primary Lymphedema

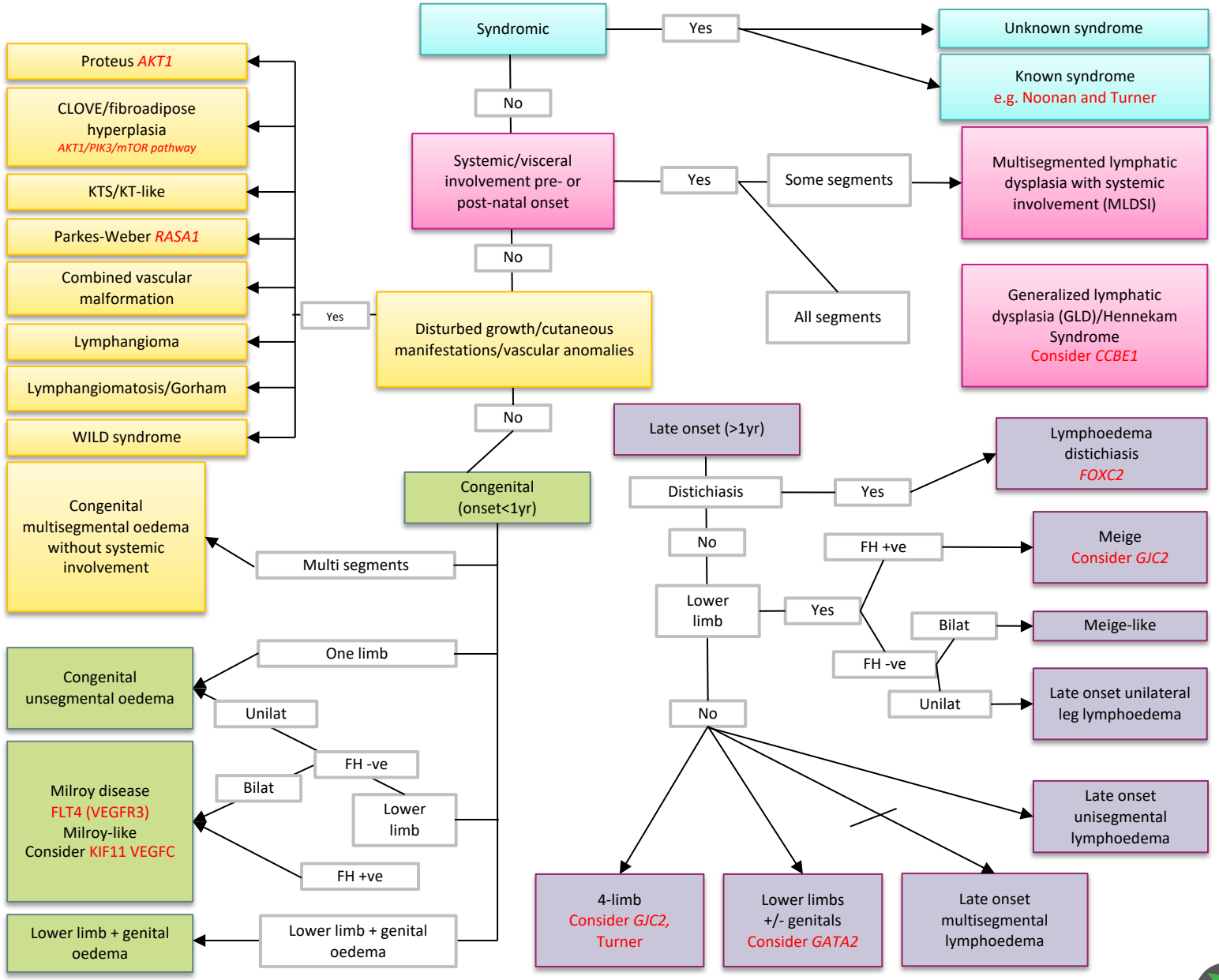
- 0.6% of all live births
- Can be present at birth or develop later (lymphedema tarda)

Lymphatic Education & Research Network. FAQS About the Lymphatic System. Last Updated unknown. Accessed May 29, 2023.
Photo Source: Instagram User Thelittlelymphie

Classification for Primary Lymphedema

"40% of those with primary lymphedema have mutations that are known."

-M. Aldrich



Adapted from: Connel F et al. The classification and diagnostic algorithm for primary lymphatic dysplasia: an update from 2010 to include molecular findings.Clin Genet 2013
Aldrich, M. Why are some people walking time bombs for developing lymphedema? LE&RN, July, 2020.

Secondary Lymphedema (Acquired)

Most Common Causes:

- Morbid obesity
- Cancer
- Disability/chair bound
- Non-cancer surgeries
- Venous insufficiency (phlebolymphedema)

Less Common Causes:

- Trauma
- Sports injuries
- Paralysis
- Liposuction
- Tattooing
- Filariasis (parasitic worms spread by mosquitos)

Keast D., Towers A. The risking prevalence of Lymphedema in Canada: A Continuing Dialogue. Lymphedema Pathways. Spring 2017. 5-8.
Image Source: Instagram user Mackenzie Kwak Parasitologist

Diagnosing Lymphedema

Consider:

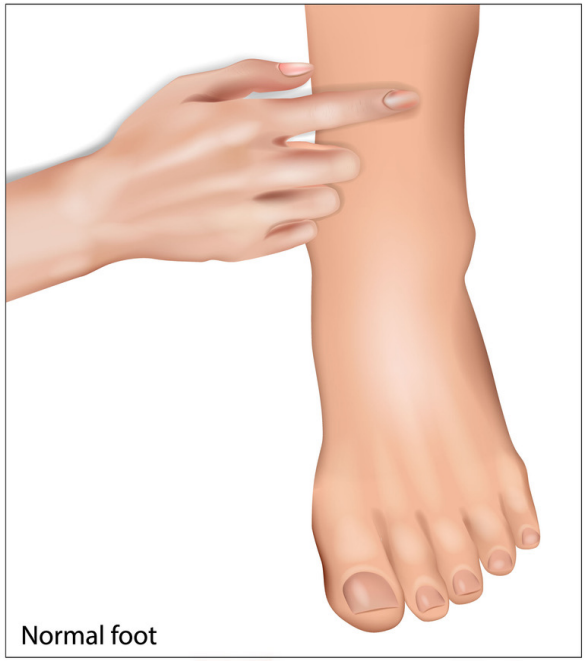
- Personal and family history of swelling
- History of lymphatic injury/surgery (any surgery not just cancer)
- Minimally responsive to limb elevation
- Minimally responsive to diuretics
- Unilateral swelling

Tests:

- Pitting
  - Edema or lymphedema
- Ultrasound to rule out/in vascular disease
- Lymphoscintigraphy - Radiolabeled technetium sulfur colloid
- Lymphography - Indocyanine green (ICG)

Stemmer Sign

- If you **CAN** pinch and tent the tissue = - Stemmer sign
- Can **NOT** pinch and tent the tissue= + Stemmer sign
- Positive stemmer sign = lymphedema


Normal foot


Pitting Edema

NSW Agency for Clinical Innovation. *Lymphoedema: A guide for clinical services*. Chatswood: ACI; 2018

Lymphedema Co-Morbidities

Lymphedema & Obesity

Obesity-Induced Lymphedema Lymphoscintigraphy Study

Study Outline

- 51 patients: 38 women, 13 men
- BMI >30
- Mean age 54 (14-86)
- No potential causes of lymphedema
- Lymphoscintigraphy

Findings

- BMI predicted lymphedema
- BMI>60 = lymphedema
  - 25% only one leg
  - 75% both legs
- BMI<50 = normal lymphatic function

Greene AK, Grant FD, Slavin SA, Maclellan RA. Obesity-induced lymphedema: clinical and lymphoscintigraphic features. *Plast Reconstr Surg*. 2015;135(6):1715-1719.

Obesity-Induced Lymphedema Lymphoscintigraphy Study Part II

Group 1: At Maximum Weight

Findings:

- All patients in group 1 with a BMI < 50 = normal lymphoscintigram
- All patients in group 1 with BMI>60 = abnormal lymphoscintigram
- BMI between 50-60 = 50% abnormal

Group 2: Below Maximum Weight

Findings:

- Those with abnormal lymphoscintigram had higher maximum BMI history BMI 77
- Those with normal result – maximal BMI 63

Greene AK, Grant FD, Slavin SA, Maclellan RA. Obesity-induced lymphedema: clinical and lymphoscintigraphic features. *Plast Reconstr Surg*. 2015;135(6):1715-1719.

Obesity-Induced Lymphedema Lymphoscintigraphy Study

Possible Explanations

1. Lymphatics are normal but unable to transport the high lymph volume
2. Limited mobility = less muscle contraction = less fluid transport
3. Excess subcutaneous adipose = inflammation = damaged lymph nodes and vessels
4. Elevated pressure from weight of the tissue/skin folds might collapse lymphatic vessels

Unclear if lymphedema is reversible with weight loss

Implications:

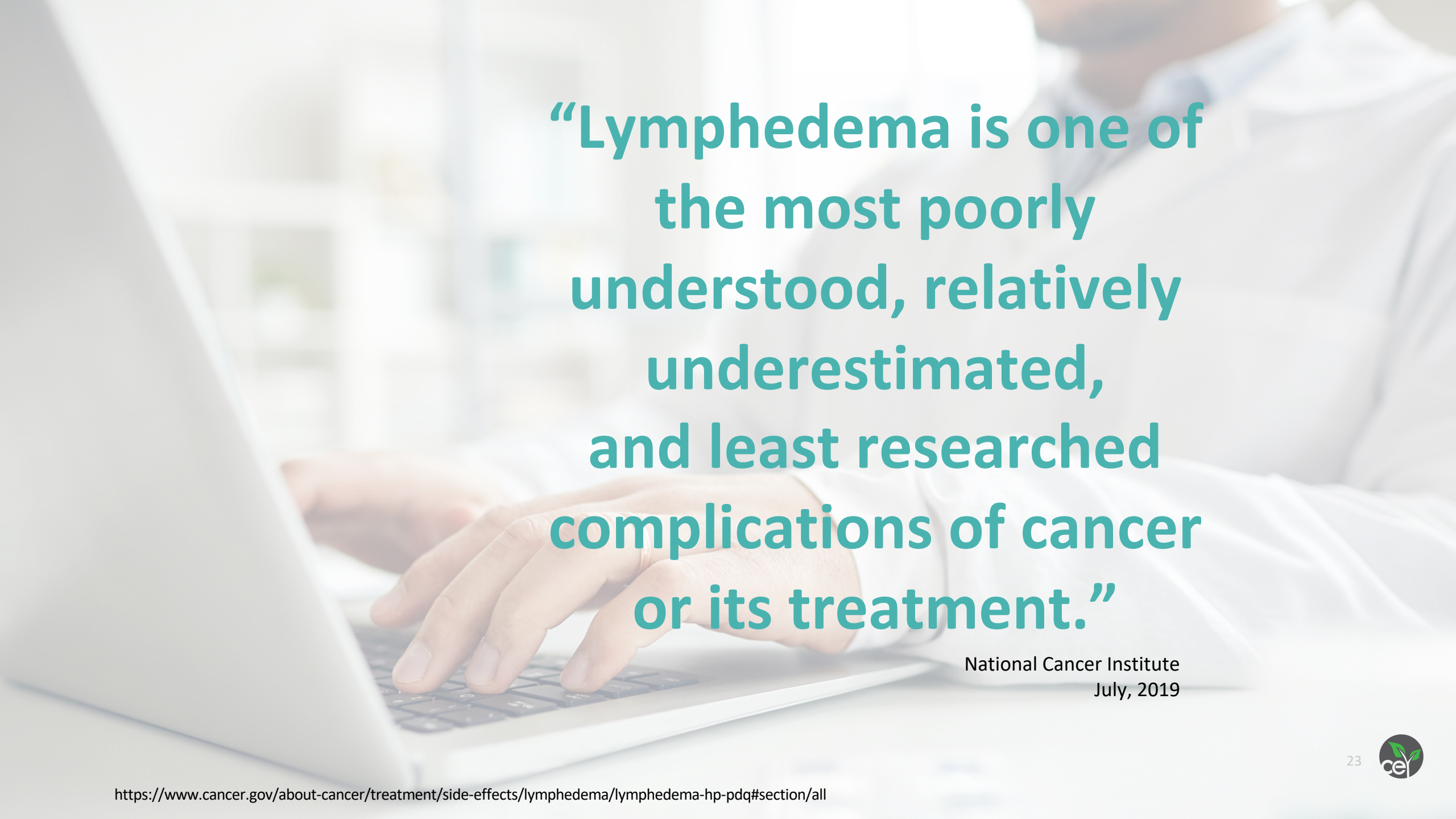
- Procedures like thigh lifts, lower extremity contouring, and inguinal incision may exacerbate lymphedema
- Prevention of weight gain or weight loss should be pursued before BMI 50 to reduce lymphedema risk

Greene AK, Grant FD, Slavin SA, Maclellan RA. Obesity-induced lymphedema: clinical and lymphoscintigraphic features. *Plast Reconstr Surg*. 2015;135(6):1715-1719.

“These studies are important because they show that obesity and lymphedema are related, and that dietary modifications or behavioral changes are an important adjunct to the treatment of the disease.”

Babak M, Kokosis G. The Link between Lymphedema and Obesity. Lymphedema Pathways. Summer 2020. https://canadalymph.ca/2020/06/16/summer-2020-pathways

Lymphedema & Cancer



“Lymphedema is one of the most poorly understood, relatively underestimated, and least researched complications of cancer or its treatment.”

National Cancer Institute
July, 2019

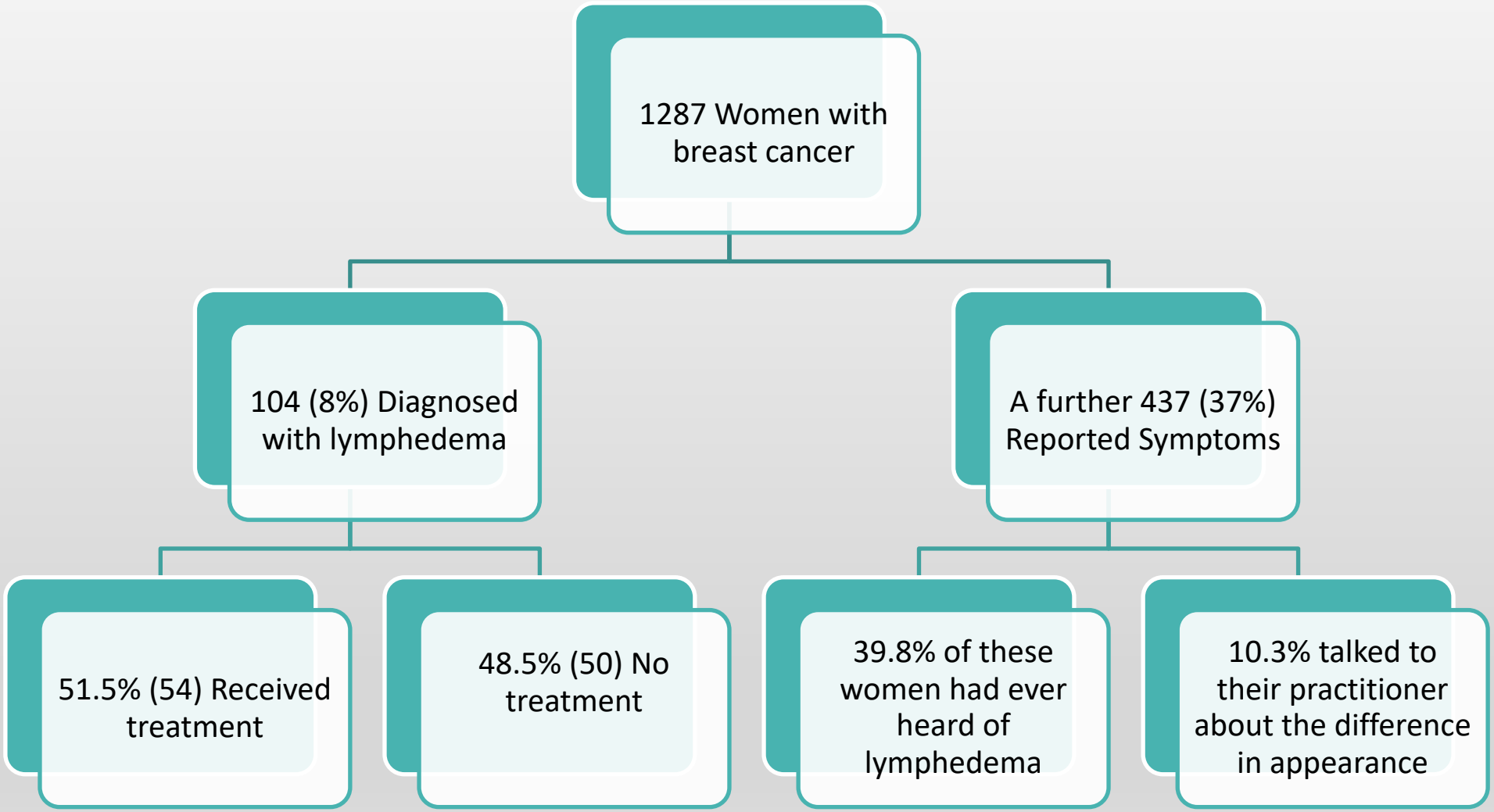
https://www.cancer.gov/about-cancer/treatment/side-effects/lymphedema/lymphedema-hp-pdq#section/all

Lymphedema After Cancer Incidence Rates

Type of Cancer	Type of Treatment	Lymphedema Incidence Rate
Head and neck cancer	Any	4.0%
Prostate cancer	Any	4.0%
Melanoma	Sentinel lymph node dissection Lymph node dissection	4.1% 9.0%
Breast cancer	Sentinel lymph node dissection Axillary lymph node dissection	6.3% 22.3%
Bladder cancer	Any	16.0%
Penile cancer	Any	21.0%
Gynecological cancer	Any	25.0%
Cervical cancer	Any	27.0%
Vulvar cancer	Any	30.0%
Sarcoma cancer	Any	30.0%

Shaitelman SF, Cronwell KD, Rasumussen JC, et al. Recent progress in the treatment and prevention of cancer-related lymphedema. CA Cancer J Clin. 2015 Jan-Feb;65(1):55-81.

Lymphedema and Breast Cancer



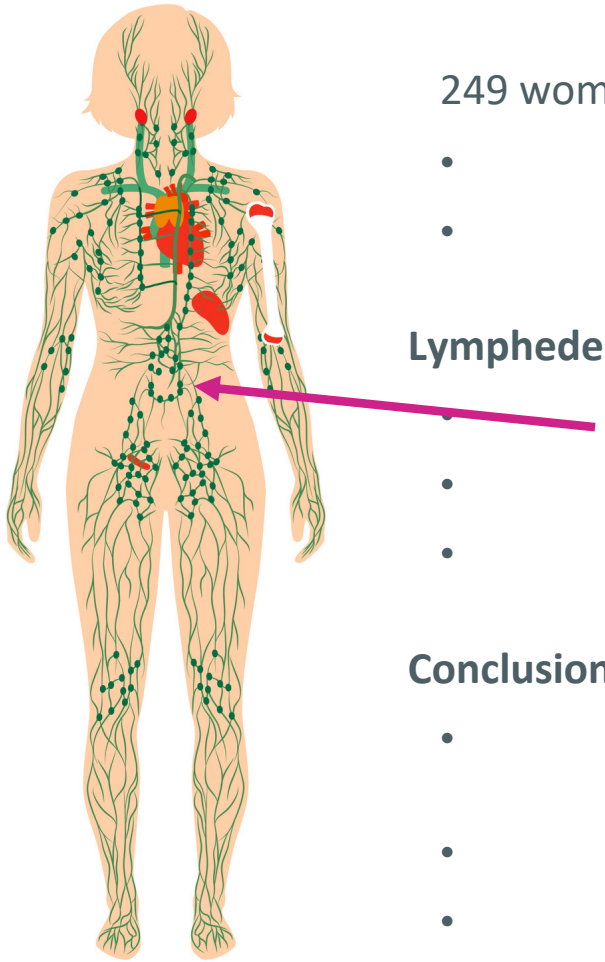
Ahmed RL, Prizment A, Lazovich D, Schmitz KH, Folsom AR. Lymphedema and quality of life in breast cancer survivors: the Iowa Women's Health Study. J Clin Oncol. 2008 Dec 10;26(35):5689-96.

Melanoma and Lymphedema

Melanoma	Type of Treatment	Lymphedema Incidence Rate
Prevalence – 300,000 cases		
Upper Body	Sentinel Lymph Node Biopsy (SLNB)	Not reported
	Axillary Lymph Node Dissection	4-15%
Lower Body	Sentinel Lymph Node Biopsy (SLNB)	8-35%
	Inguinal Lymph Node Dissection	49-83%

Arié A, Yamamoto T. Lymphedema secondary to melanoma treatments: diagnosis, evaluation, and treatments. Glob Health Med. 2020 Aug 31;2(4):227-234.

Endometrial Cancer and Lymphedema



249 woman with endometrial cancer treated with hysterectomy and lymphonodectomy in past 6 yrs

- 37% (92) developed lymphedema
- 17% (43) developed lymphocele (lymphatic fluid in retroperitoneal space)

Lymphedema Risk Factors:

- Para-aortic lymphadenectomy (in front of the lumbar vertebrae)
- Post-operative radiation
- Positive lymph nodes

Conclusions

- Previous research shows high risk patients who had pelvic and para-aortic lymphonodectomy experienced longer overall survival
- Lymph nodes dissection is current standard of care
- Sentinel lymph node biopsy is a promising option

Volpi L,, et al. Long term complications following pelvic and para-aortic lymphadenectomy for endometrial cancer, incidence and potential risk factors: a single institution experience. Int J Gynecol Cancer. 2019 Feb;29(2):312-319.
Arié A, Yamamoto T. Lymphedema secondary to melanoma treatments: diagnosis, evaluation, and treatments. Glob Health Med. 2020 Aug 31;2(4):227-234.

If Your Patient Has Lymphedema or is at Risk… Refer to a Certified Lymphedema Therapist

Complete Decongestive Therapy

1. Skin care
   - Hydration with low pH moisturizers
   - Prevention of cellulitis
2. Compression
   - Multilayer compression bandaging
   - Compression garments
3. Exercise
4. Manual lymphatic drainage

LaMantia J, DiMenna A. The Complete Lymphedema Management and Nutrition Guide. Robert Rose Books, 2018

Diet for Lymphedema

Diet for Lymphedema

- Body weight
- Fats and oils
- Healthy gut and bowel routine
- Wound healing
- Fluid
- Sodium
- Protein
- Anti-inflammatory
- Time restricted eating

Most Research

Least Research

Research and Findings

Study	Participant Details	Nutrition-Related Risk Factors
Treves; 1957	1,007 women and men with arm lymphedema after cancer surgery	Obesity is a predisposing factor: the greater the obesity, the greater percentage of patients with lymphedema
Petrek, 2001	263 women post mastectomy and complete axillary for 20 years	Weight gain since operation was significant risk factor
Geller, 2003	145 women with invasive breast cancer	No association with body weight Significantly decrease risk when on treatment for high blood pressure
Clark; 2005	251 women who had surgical treatment for breast cancer	BMI of 26 or more
Mak, 2008	202 women unilateral axillary dissection for breast cancer	Obesity and BMI
Meeske, 2009	494 women (271 white, 223 black)	BMI and high blood pressure
Helyer, 2010	137 breast cancer patients	BMI>30 = 2.93 odds ratio of developing lymphedema vs BMI<25
Ahmed; 2011	1,287 women with breast cancer on one side	Higher the BMI, the greater the risk Higher the waist:hip circumference the greater the risk Poor general health
Ridner; 2011	138 newly diagnosed breast cancer survivors	BMI of 30 or more at treatment
Greene; 2012	15 obese people	BMI of 54 or more showed lower leg lymphedema;

Research and Findings (cont.)

Study	Participant Details	Nutrition-Related Risk Factors
Huang; 2012	126 postmenopausal breast cancer participants with mastectomy	BMI of 25 or more
Dominick, 2013	692 women after breast cancer treatment	BMI of 25 or more
Jammallo; 2013	787 breast cancer patients	BMI of 30 or more before treatment 10 lb weight gain or loss in 1 month
DiSipio; 2013	29 studies published between Jan. 1, 2000, and June 30, 2012	Being overweight or obese identified as a strong contributing risk factor for lymphedema
Mahrara; 2014	23 articles reviewed	Reciprocal relationship: lymphedema leads to obesity and obesity contributes to lymphedema
Togawa, 2014	666 women with breast cancer	Pre-treatment BMI>30 vs BMI<25 High blood pressure in African-American women
Rebegeal; 2015	305 breast cancer patients	Obesity, diabetes and high blood pressure were not found be to risk factors. Follow-up term not specified.
Kilbreath; 2016	450 women who had breast cancer surgery and lymphonodectomy	Overweight
Armer, 2019	701 women with axillary node metastasis with neoadjuvant chemotherapy	Obesity and increasing BMI

Weight Loss Clinical Trials

Diets:

- 1200 Kcal (2 studies) (Shaw and Shaw, 2007)
- Nutrisystem (Schmitz, 2019)
- Keto-ish (Keith, 2017)
- -500 kcal plus synbiotic or placebo (Vafa, 2020)

4 out of 5 studies show reduction in lymphedema with weight loss

1.Shaw C, Mortimer P, Judd PA. A randomized controlled trial of weight reduction as a treatment for breast cancer-related lymphedema. Cancer. 2007 Oct 15; 110 (8): 1868–74.
2.Shaw C, Mortimer P, Judd, PA. Randomized controlled trial comparing a low-fat diet with a weight-reduction diet in breast cancer-related lymphedema. Cancer. 2007 May 15; 109 (10): 1949–56.
3.Keith L, Rowsemitt C, Richards L. Lifestyle Modification Group for Lymphedema and Obesity Results in Significant Health Outcomes. American Journal of Lifestyle Medicine. 2017.
4.Schmitz K, Troxel A, Dean L et al. Effect of Home-Based Exercise and Weight Loss Program and Breast Cancer-Related Lymphedema Outcomes Among Overweight Breast Cancer Survivors The WISER Survivor Randomized Clinical Trial. JAMA Oncology. August 15, 2019. E1-E9.
5.Vafa S, Haghighat S, Janani L, Totmaj AS, Navaei M, Amirinejad A, Emamat H, Salehi Z, Zarrati M. The effects of synbiotic supplementation on serum inflammatory markers and edema volume in breast cancer survivors with lymphedema. EXCLI J. 2020 Jan 2;19:1-15.

Digestion and Absorption of Dietary Fats

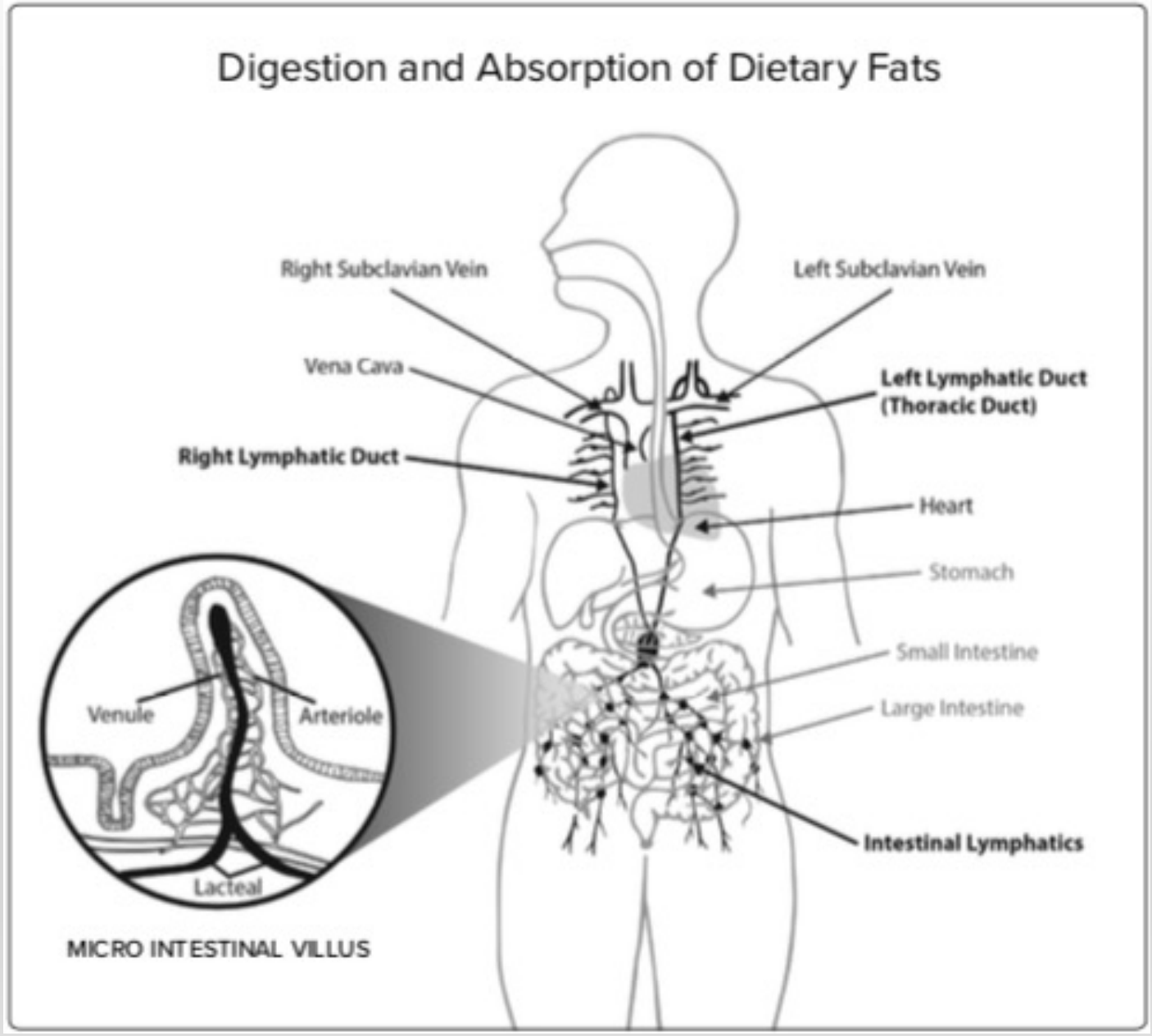


Image source: LaMantia, J, Dimenna, A. et al. (2019*) The complete lymphedema management and nutrition guide: empowering strategies, supporting recipes and therapeutic exercise.* Robert Rose.

Triglyceride Chain Length

	Triglyceride Chain Length		
Type of Oil	Short-chain (< 6 carbons)	Medium-chain (6–12 carbons)	Long-chain (13–21 carbons)
MCT oil	0	100%	0
Coconut oil	0	64%	36%
Palm kernel oil	0	55%	42%
Butter	5%	7%	89%
Canola oil	0	0	100%
Corn oil	0	0	100%
Flaxseed oil	0	0	100%
Olive oil	0	0	100%
Palm oil	0	0	100%
Safflower oil	0	0	100%
Sesame oil	0	0	100%
Soybean oil	0	0	100%
Sunflower oil	0	0	100%

Orsavova J, Misurcova L, Ambrozova JV, Vicha R, Mlcek J. Fatty Acids Composition of Vegetable Oils and Its Contribution to Dietary Energy Intake and Dependence of Cardiovascular Mortality on Dietary Intake of Fatty Acids. Int J Mol Sci. 2015 Jun 5;16(6):12871-90.

Berger KG. Palm Kernel Oil. Encyclopedia of Food Sciences and Nutrition, second edition. 2003

Fluid Loss and Thirst

- Water is lost
- Ionic concentration increases
- Intracellular space yields water to extracellular space
- Shrinking intracellular cells send message to brain
- Thirst and salt appetite

Popkin BM, D'Anci KE, Rosenberg IH. Water, hydration, and health. Nutr Rev. 2010 Aug;68(8):439-58.

Other Nutrition Tools

- Protein
- Wound healing
- Anti-inflammatory
- Time restricted eating

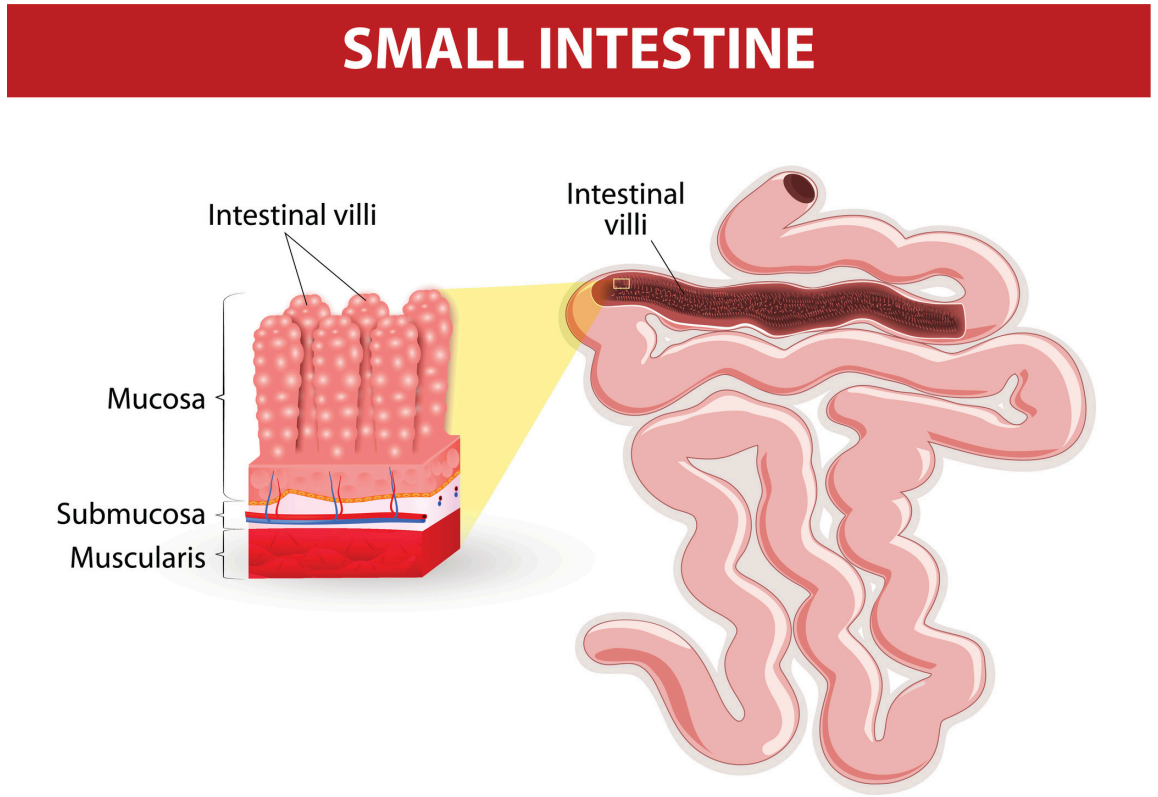
The Small Intestine and The Lymphatic System

The Villi, Lacteals and Mesenteric Lymph Nodes, and The Microbiota

The Villi

Contains smooth muscles, which;

- Perform a cyclic contraction-relaxation activity to create a pumping mechanism for lymph propulsion
- Release VEGF-C which maintains lacteal integrity and proper lymph drainage function



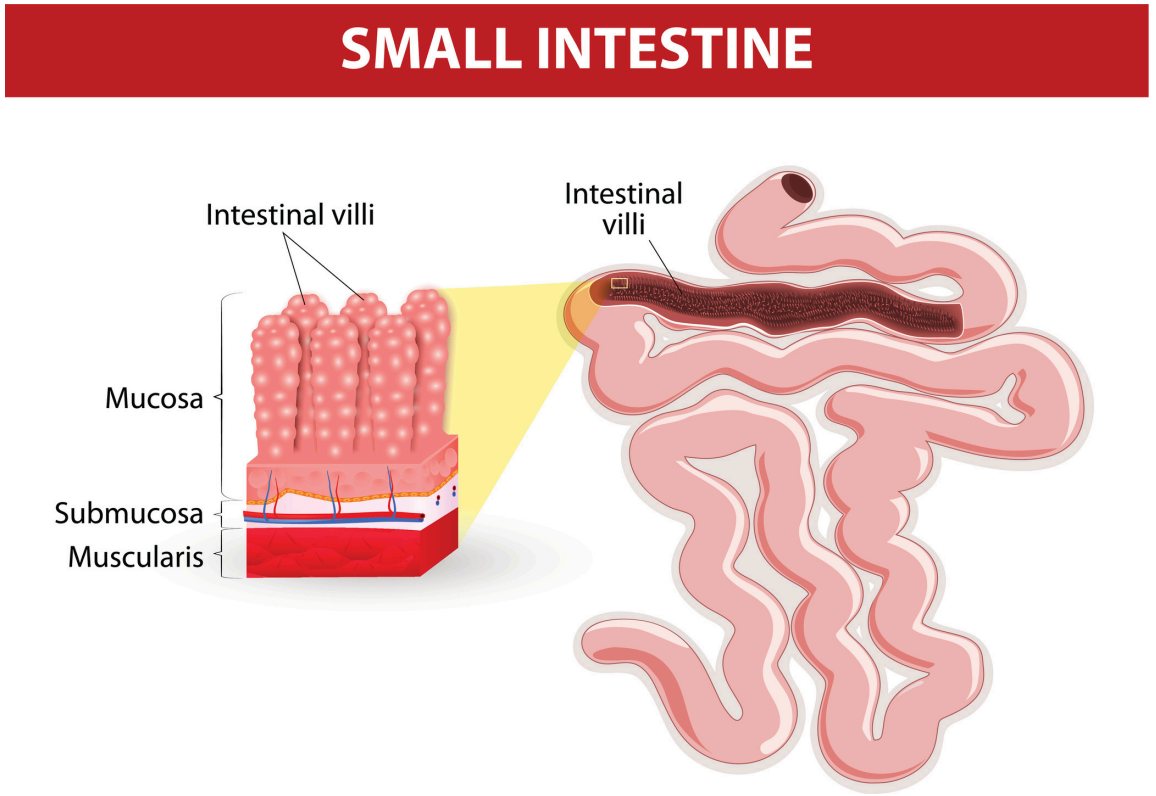
VEGF-C = Vascular endothelial growth factor C

- Responsible for prenatal lymphatic system development
- Adult lymphatic maintenance

Solari E, et al. Interplay between Gut Lymphatic Vessels and Microbiota. Cells. 2021 Sep 28;10(10):2584.

Lacteals and Mesenteric Lymph Nodes

- One lacteal per intestinal villi
- They merge at the base of the villa in the submucosa (the smooth muscle layer surrounding the mucosa)
- They are non-contracting
- They have no lymphatic muscle
- They are constantly remodeling



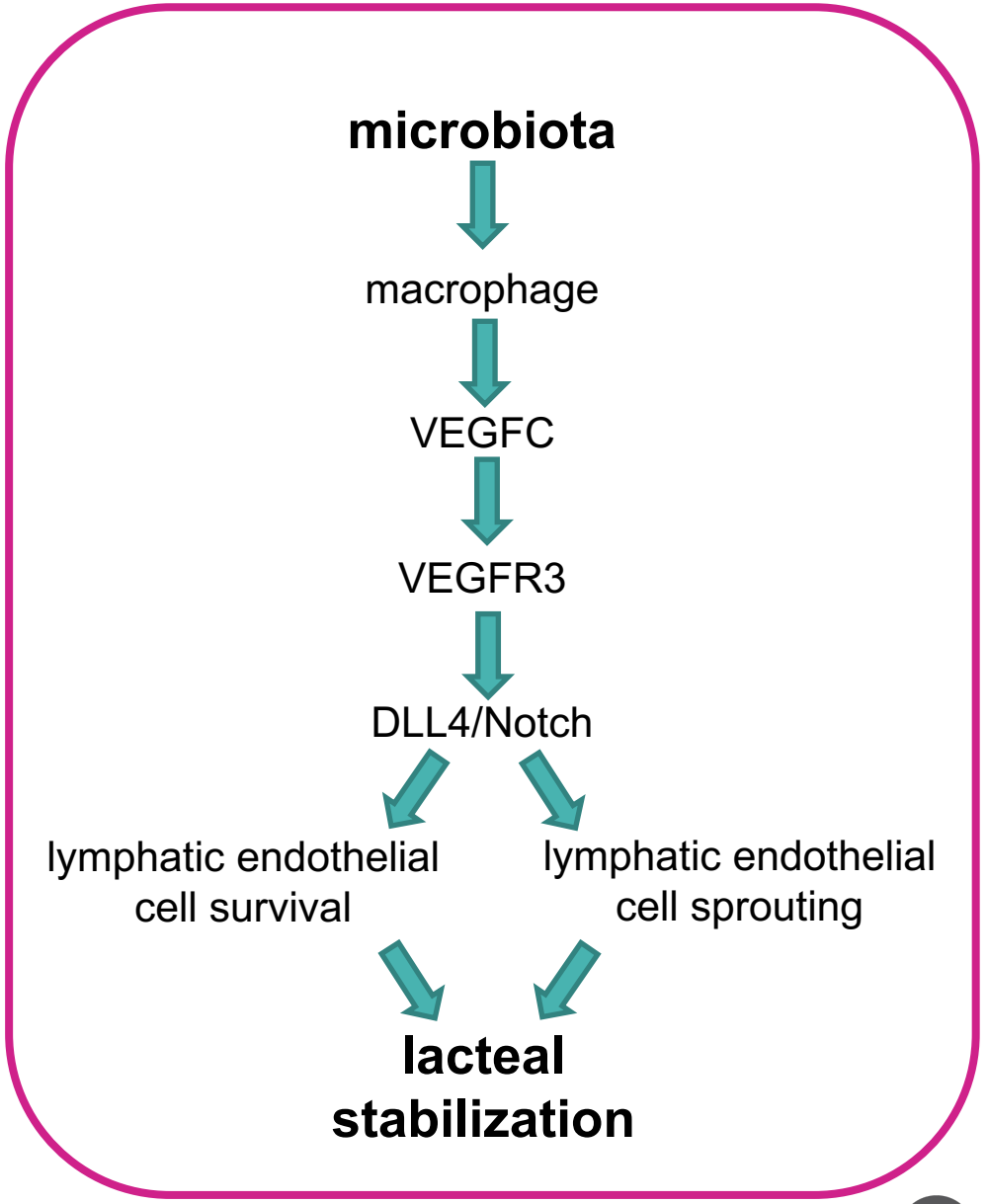
Solari E, et al. Interplay between Gut Lymphatic Vessels and Microbiota. Cells. 2021 Sep 28;10(10):2584.

The Microbiota

- A key player in the normal development and maintenance of adult lacteals
- The gut microbiota interacts with intestinal villi
- It seems likely that gut microbiota can control the number of macrophages, which controls the level of VEGF-C, which controls lacteal sprout and stabilization (mouse research)

VEGF-C = Vascular endothelial growth factor C

- Responsible for prenatal lymphatic system development
- Adult lymphatic maintenance



Solari E, et al. Interplay between Gut Lymphatic Vessels and Microbiota. Cells. 2021 Sep 28;10(10):2584.
Image adapted from Solari et al. Interplay between Gut Lymphatic Vessels and Microbiota. Cells. 2021 Sep 28;10(10):2584.

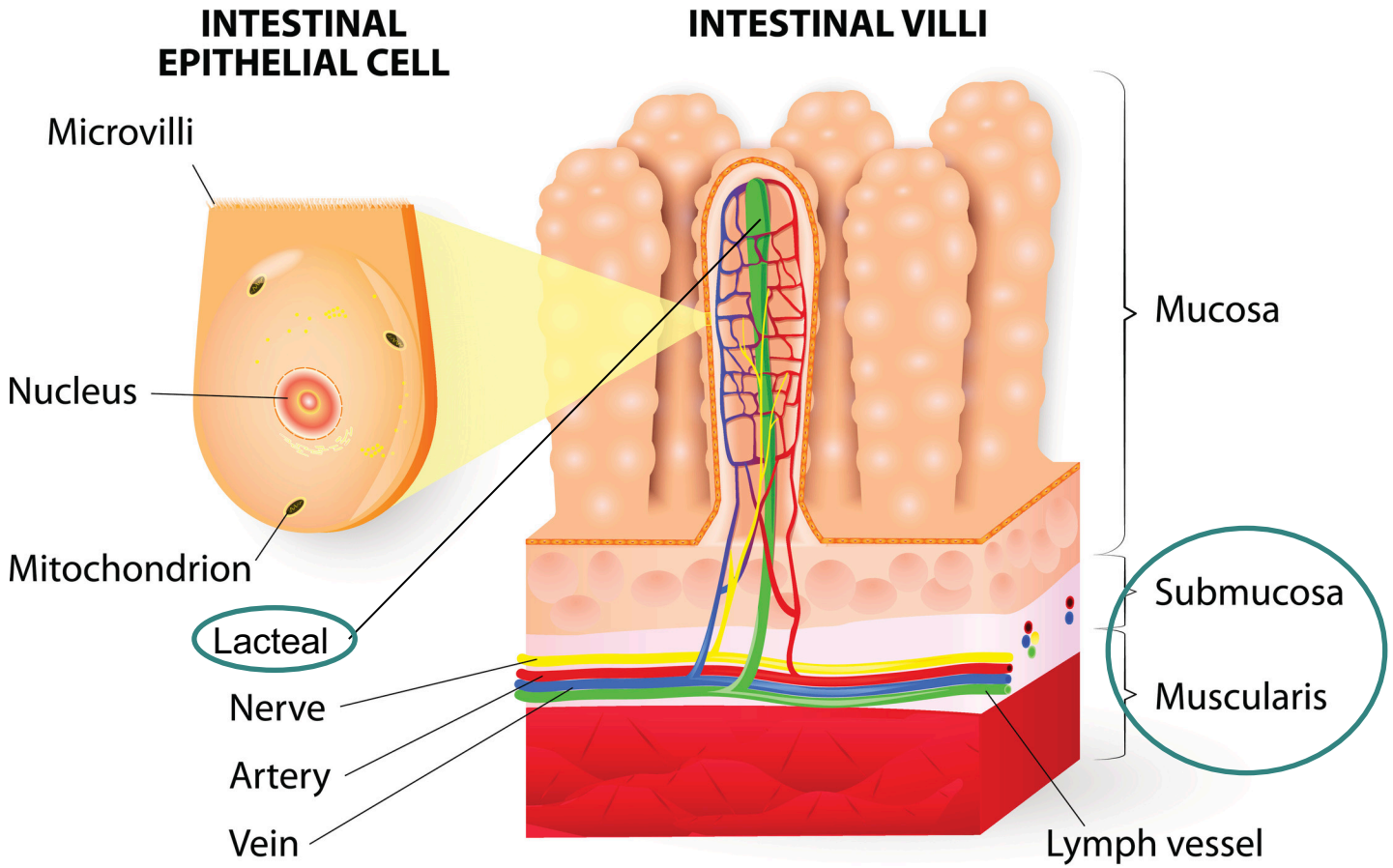
Lacteals and Submucosa/Mesentery

2 Main Locations:

1. Lacteals in the intestinal villi
2. Collecting lymphatics in the submucosa/mesentery

Mesentery: a fold of skin that attaches the intestines to the abdominal wall.

Lymph nodes in the intestines are one of the largest groups in the body.



Solari E, et al. Interplay between Gut Lymphatic Vessels and Microbiota. Cells. 2021 Sep 28;10(10):2584.

Clinician Bottom Line

Lymphedema

- Can be primary or secondary
- Any person with lymph nodes removed has a lifelong risk of lymphedema
- Obesity >BMI 60 has 100% lymphedema
- There is no cure
- Lymphedema is chronic and progressive
- Complete decongestive therapy is the main treatment

Interdisciplinary Approach

Refer to a Certified Lymphedema Therapist

If they need a diagnosis refer to vascular doctor

They may benefit from referral to pharmacist, psychological support, wound care, skin care, speech language pathologist, social worker, exercise specialist

Nutrition therapy by a registered dietitian should be included in the interdisciplinary team

Diet for Lymphedema Summary

- Body weight
  - Excess weight is a risk factor
  - Weight loss improved lymphedema in 4/5 studies
- Fats and oils
  - The lymphatic system is needed to transport dietary long chain fatty acids
  - 1 case study and 1 small clinical trial showed improved with low fat diet and MCT oil
- Healthy gut and bowel routine
  - Lymphatics and intestines are closely reliant
  - One weight loss trial with synbiotic supplement showed improved vs control for lymphedema reduction and inflammation
- Wound healing
  - People with lymphedema are at higher risk of wounds
  - Nutrition screening and intervention is prudent
- Fluid
  - Do not restrict
- Sodium
  - Restrict
- Protein
  - Protein + exercise to build and maintain healthy muscle
- Anti-inflammatory
  - Inflammation is an an inflammatory condition and while not tested on this population, an anti-inflammatory diet is safe and effective
- Time restricted eating
  - No clinical trials but several rationale for this: reduced inflammation, weight loss, bowel rest, lower blood pressure

Lipedema

Lymphedema and Lipedema

Lymphedema

Accumulation of protein rich lymphatic fluid

1

Lipedema

Uncontrolled growth of painful nodular fatty tissue. A connective tissue disease.

2

Photo source: 1. LaMantia, J, Dimenna, A. et al. (2019*) The complete lymphedema management and nutrition guide: empowering strategies, supporting recipes and therapeutic exercise.* Robert Rose.
2. National Health Services (England), https://www.nhs.uk/conditions/lipoedema/

Diagnosing Lipedema

Diagnosing Lipedema

- Family history
  - Grandma had “stove pipe legs”
- Medical testing
  - Rule out lymphedema with lymphoscintigraphy (or confirm lipo-lymphedema)
  - Rule out peripheral vascular disease with ultrasound (or rule in as common co-morbidity)
- Genetic Testing
  - Autosomal dominant inheritance with sex limitation to mostly women
  - Gene mutation AKR1C1 – a version with lipedema and no pain
  - Genetic mapping is ongoing

Herbst KL, Kahn LA, Iker E, et al. Standard of care for lipedema in the United States. Phlebology. 2021 Dec;36(10):779-796.

Lipedema Types and Stages

Type 1
- Buttocks
- Hips, “Saddlebags”

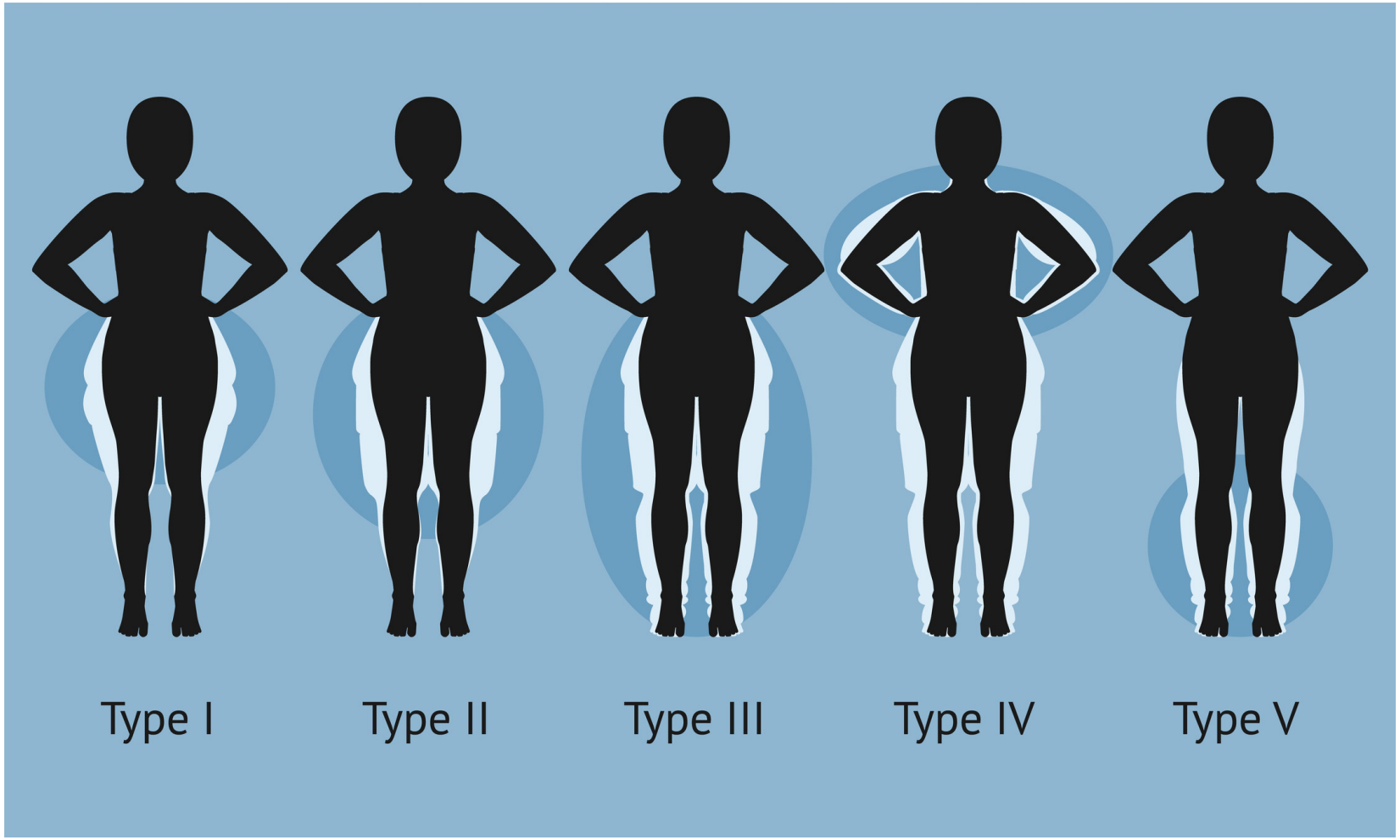
Type 2
- Buttocks to knees
- Folds of fat around inner knee

Type 3
- Buttocks to ankles

Type 4
- Arms

Common combinations:
- Type 2 and 4
- Type 3 and 4

Type 5
- Lower legs



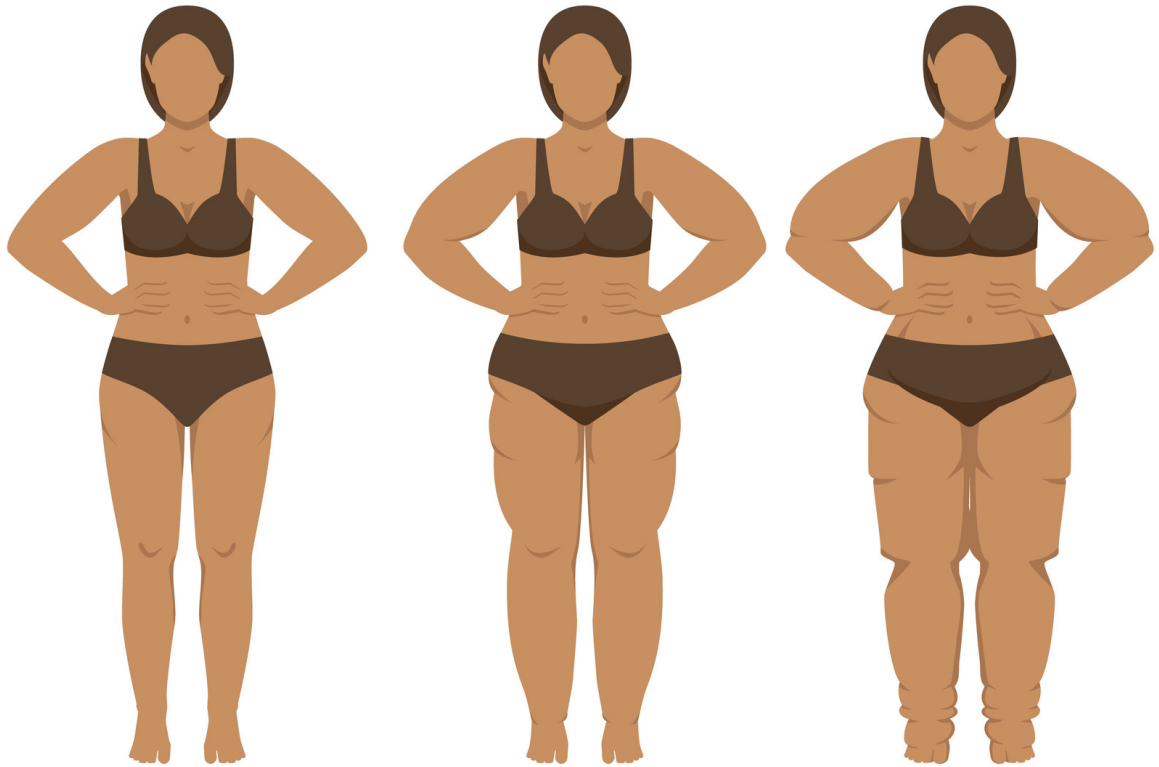
https://www.lipoedeembelgie.be/leven-met-lipoedeem/levensfasen/

Stages of Lipedema

Stage 1
Thickened subcutis, soft, small palpable nodules, skin surface still smooth

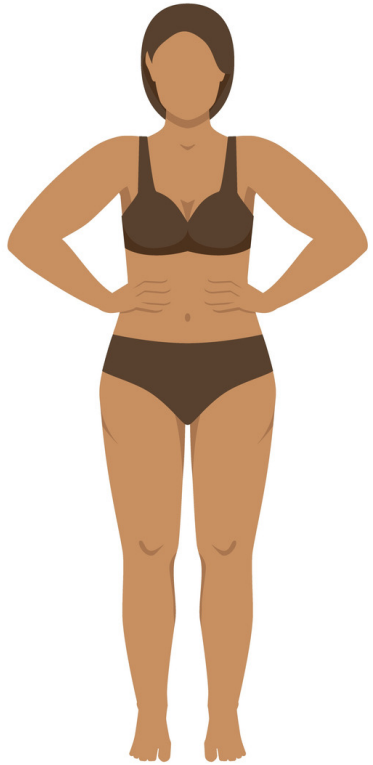
Stage 2
Thickened subcutis, soft, larger nodes, uneven skin surface, wavy

Stage 3
Thickened subcutis, indurated, large nodules with pronounced sclerosis, deforming fat lobes



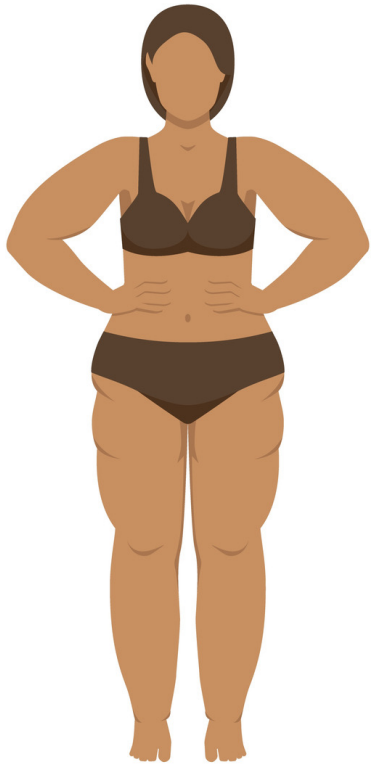
Ghods M, et al.. Dermatol Ther. 2020 Nov;33(6):e14534.

Lipedema Staging



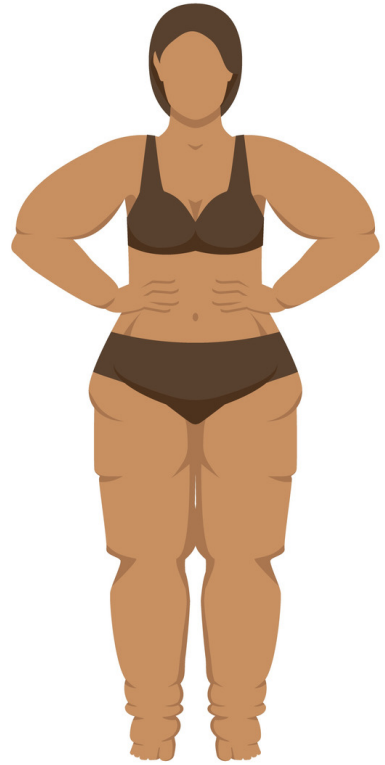
Stage 1

Skin looks normal, but is spongy when touched



Stage 2

Large fat deposits with indentations form, especially around knees and ankles



Stage 3

Fat deposits on legs are bulky, hanging over hips, knees and ankles, fibrous and harder

Herbst KL, Kahn LA, Iker E, et al. Standard of care for lipedema in the United States. Phlebology. 2021 Dec;36(10):779-796.

Fat Nodules

- Can feel like “peas”
- Lipomas

or

- Can look like orange peel texture (Peau d’orange) ie. thick and pitted skin

Photo Source: Instagram user @**so_many_cats_so_little_time**

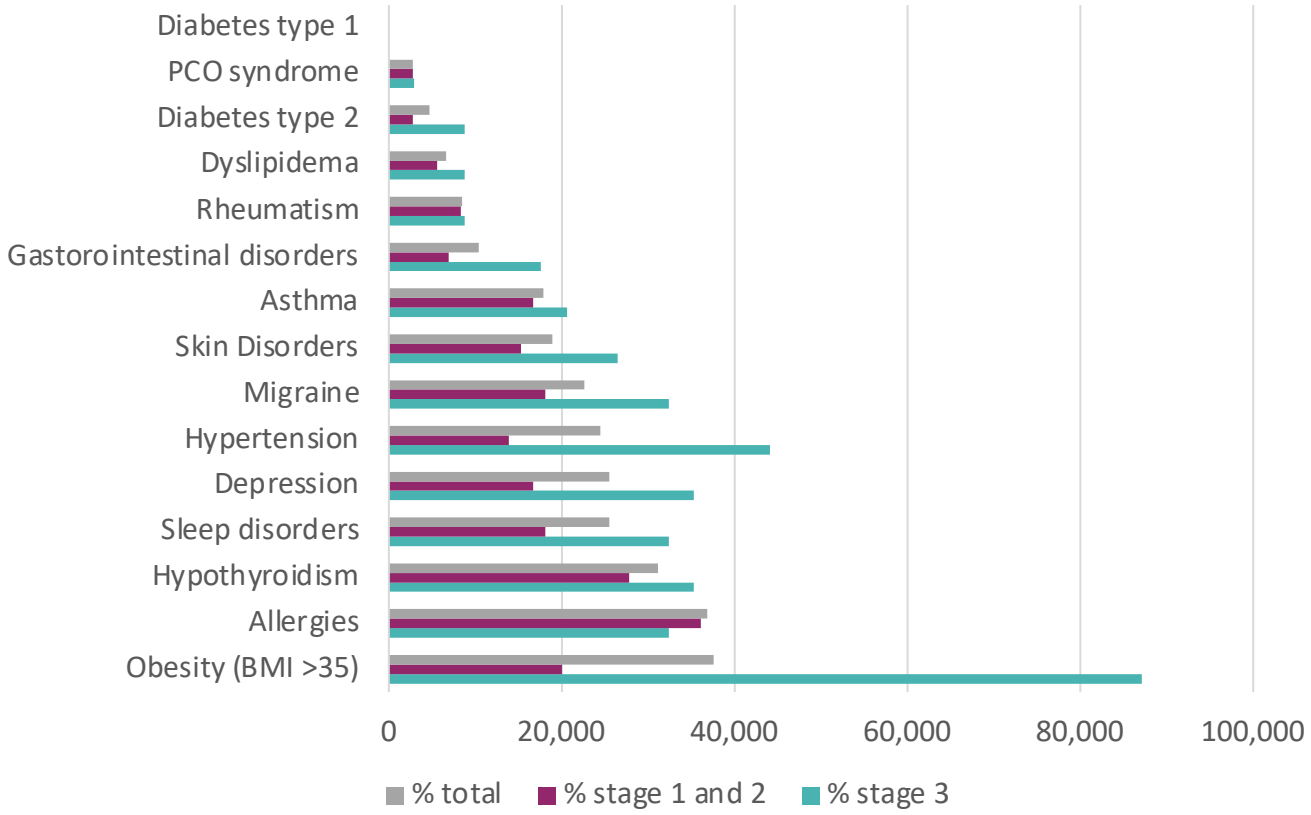
Concurrent Conditions

- Ehlers Danlos Syndrome
  - Inherited connective tissue disorder
  - Overly flexible joints and stretchy, fragile skin
- Lymphedema
- PCOS
- Non-lipedema obesity (88% at Földi clinic)
- Venous disease
  - Thromboembolism
  - Varicose veins
  - Chronic venous insufficiency
  - Spider veins
  - Deep vein thrombosis
- Lipomas
- Sleep apnea
- Depression (18-35%), anxiety (18-30%), eating disorders (74%)
- Migraines
- Diabetes (5%) (less than obesity)
- Dyslipidemia (7%) (less than obesity)

Herbst KL, Kahn LA, Iker E, et al. 2021 Dec;36(10):779-796.
Ghods M, et al.. Dermatol Ther. 2020 Nov;33(6):e14534.
Photo source: Instagram user, @esteticasusanadias

Common Lipedema Comorbidities

Prevalence of common comorbidities in lipedema, percentage. *PCO syndrome



*polycystic ovary

- 88% have at least 1 comorbidity
- The number and extent of comorbidities increases as the lipedema stage advances
- "The earliest possible diagnosis is of crucial importance for optimal long-term therapy"

Ghods M, Georgiou I, Schmidt J et al. Disease progression and comorbidities in lipedema patients: A 10-year retrospective analysis. Dermatol Ther. 2020 Nov;33(6):e14534.
Graph adapted from: Ghods M, Georgiou I, Schmidt J et al. Disease progression and comorbidities in lipedema patients: A 10-year retrospective analysis. Dermatol Ther. 2020 Nov;33(6):e14534.

"Obesity is very common and in the limited time allotted to patient care, it may be easy to misdiagnose a patient with a Rare Adipose Disease as having simple obesity."

Herbst KL. Rare adipose disorders (RADs) masquerading as obesity. *Acta Pharmacol Sin*. 2012;33(2):155-172.

Diet for Lipedema

Current Recommendations from Fat Disorders Dot Org

Adapted from: https://www.fatdisorders.org/treatments-summary

Nutrition

RAD diet
Rare Adipose Disorder, by Dr. Karen Herbst

- No red meat
- No dairy
- No sweets
- No potato, white flour, white rice (labelled “simple carbs”)
- No hydrogenated fats
- No high fat foods- mayo, fried foods, salad dressing
- Fat should be <30% of calories
- No sugar or artificial sweeteners
- Organic fruits and veggies
- No pasteurized dairy

Herbst KL. RAD Diet. Lipomadoc dot org. Last updated April 18, 2012. Accessed May 29, 2023. http://www.lipomadoc.org/blog/rad-diet

Modified Mediterranean Diet

Nutrition Research

- 29 women
  - 14 lipedema
  - 15 controls
- No significant difference between groups at baseline for:
  - Age, height, weight, BMI, circumferences
  - W:H ratio, Bioelectrical impedance and extracellular water were significantly different
- Modified Mediterranean Diet for all for 4 weeks

Di Renzo L, Cinelli G, Romano L, et al. Potential Effects of a Modified Mediterranean Diet on Body Composition in Lipoedema. Nutrients. 2021 Jan 25;13(2):358.

Modified Mediterranean Diet

- Hypocaloric modified Mediterranean diet
  - 40-45% CHO
  - 25-30% PRO (>50% veg)
  - 25-30% FAT
- Primary plant based
- Seasonal fruits and veggies
- Whole grains
- Legumes and nuts
- Olive oil in place of butter
- Herbs and spices in place of salt
- Avoided: preserved and processed foods, cured meats, canned foods, frozen meals, cheese (except ricotta), potatoes, high GI carbs, alcohol, sweetened drinks

Di Renzo L, Cinelli G, Romano L, et al. Potential Effects of a Modified Mediterranean Diet on Body Composition in Lipoedema. Nutrients. 2021 Jan 25;13(2):358.

Modified Mediterranean Diet

Results

Control Group	Lipedema Group	Control vs. Lipedema Group
Weight, BMI, neck, waist, hip circumference and Waist:Hip ratio were significantly reduced Greatest loss of fat is from in the truncal area	Weight and BMI significantly reduced Fat was lost from arms and legs (unexpected finding) Increased ability to perform ADL (thought to be due to loss of lippy fat from arms and legs) Less fatigue, pain and anxiety while performing ADL (thought to be due to loss of lippy fat from arms and legs) Did not see reduced REE (as previously published)	Significant difference in waist circumference

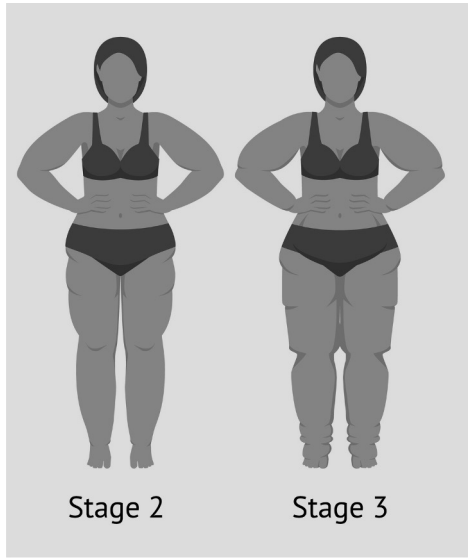
Di Renzo L, Cinelli G, Romano L, et al. Potential Effects of a Modified Mediterranean Diet on Body Composition in Lipoedema. Nutrients. 2021 Jan 25;13(2):358.

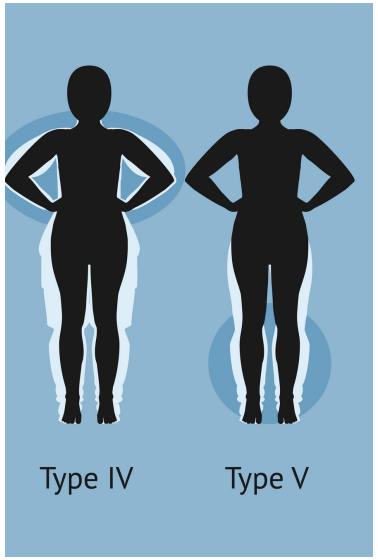
Ketogenic Diet

Nutrition Research

Case Study

- 32 y.o. woman with lipedema type IV-V, stage 2-3
  - Type IV- arms
  - (looks like type II+ IV or III+IV)
- Widespread pain, heaviness and difficulty moving
- 200-250 kcal deficient
- 25 grams carb per day
- 22 months





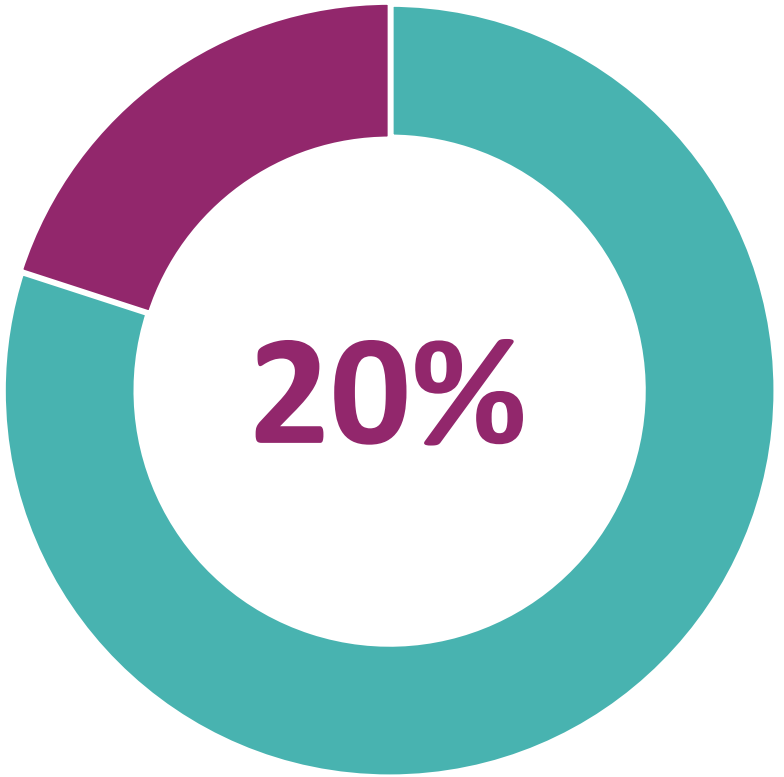
Before and after photos available in the publication

Cannataro R, Michelini S, Ricolfi L, et al. Management of Lipedema with Ketogenic Diet: 22-Month Follow-Up. *Life (Basel)*. 2021;11(12):1402. Published 2021 Dec 15

Nutrition Research Ketogenic Diet

Case Study Results

- Lost 41 kg (90 lbs)
- Reduced 20% body fat
- Significant reduction in insulin
- Reduced CRP
- Improved quality of life
- Improved quality of sleep

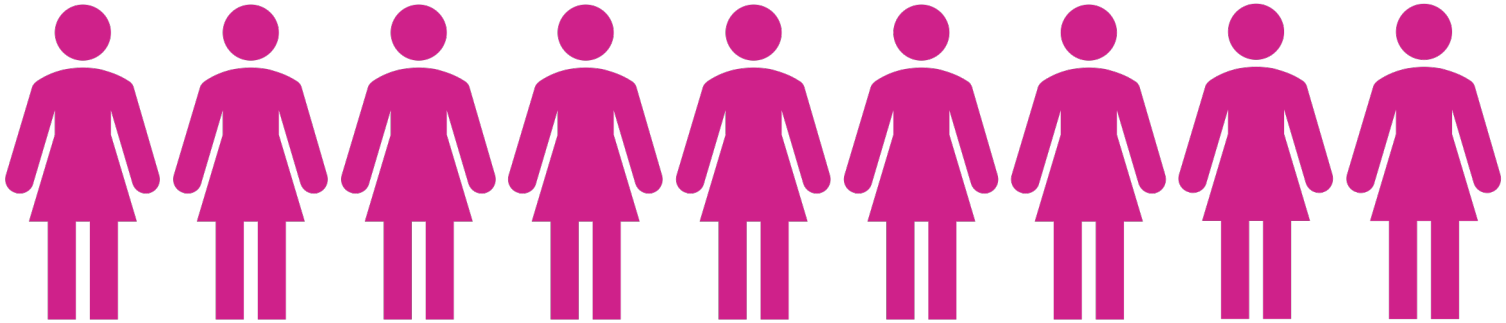


Cannataro R, Michelini S, Ricolfi L, et al. Management of Lipedema with Ketogenic Diet: 22-Month Follow-Up. *Life (Basel)*. 2021;11(12):1402. Published 2021 Dec 15

Keto and Lipedema

Norwegian Study

- 9 women, BMI between 30-45 kg/m^2
- A variety of types and stages of lipedema in their legs
- 7 weeks of keto diet followed by 6 weeks Nordic Nutrition Recommendations diet, with both diets being equal in calories
- Asked not to change their usual activity



Sørlie V, De Soysa AK, Hyldmo ÅA, Retterstøl K, Martins C, Nymo S. Effect of a ketogenic diet on pain and quality of life in patients with lipedema: The LIPODIET pilot study. Obes Sci Pract. 2022 Apr 21;8(4):483-493.

Keto and Lipedema

Norwegian Study

Results

Variable	Baseline to Week 7	Week 7 to 13
Body weight	- 4.6 +/- 0.7 kg ^	- 4.1 +/-0.7 kg^^
Waist	- 4/3 cm*	+2 cm
Hip	-2.2 cm*	No change
Calf	-1.0 cm*	+0.5 cm
Thigh	-2.0 cm*	+0.1 cm
Body water	-2.9 L	+0.5 L

*statistically significant
^ 1.5 – 2 kg attributed to loss of glycogen and fluid from muscle
^^ some is due to fluid and glycogen returned to muscle

Sørlie V, De Soysa AK, Hyldmo ÅA, Retterstøl K, Martins C, Nymo S. Effect of a ketogenic diet on pain and quality of life in patients with lipedema: The LIPODIET pilot study. Obes Sci Pract. 2022 Apr 21;8(4):483-493.

Keto and Lipedema
Norwegian Study

Study Results

- Keto diet resulted in significant reduction in pain from baseline to week 7
- Pain returned to baseline by week 13
- Significant increase in quality of life from baseline to week seven
- No correlation between weight loss and pain even when weight loss was maintained

Sørlie V, De Soysa AK, Hyldmo ÅA, Retterstøl K, Martins C, Nymo S. Effect of a ketogenic diet on pain and quality of life in patients with lipedema: The LIPODIET pilot study. Obes Sci Pract. 2022 Apr 21;8(4):483-493.

Why was there pain reduction in the Norwegian Study participants ?

Keto and Lipedema
Norwegian Study

Why was there pain reduction?

Theories:

1. Pain reduction is due to ketosis and not weight loss.
2. Keto diet in this study was high omega-3 and anti-inflammatory (as seen in Mediterranean diet study).
3. Loss of non-lipedema fat relieved pressure on the blood vessels.

Sørlie V, De Soysa AK, Hyldmo ÅA, Retterstøl K, Martins C, Nymo S. Effect of a ketogenic diet on pain and quality of life in patients with lipedema: The LIPODIET pilot study. Obes Sci Pract. 2022 Apr 21;8(4):483-493.

Keto and Lipedema Study #2

Poland Study

91 women were assigned to one of two diets:

- Keto diet (46 women)
- Low glycemic index, medium carbohydrate, medium fat diet (45 women)
- 15-25% calorie deficit divided into 3-5 meals with overnight fasting of a minimum of 12 hours
- Both diets had a high level of unsaturated fats, including olive oil, almonds, hazelnuts, avocados, olives, canola oil, flaxseed oil, walnuts, herring, sardines, salmon and mackerel
- The diets were followed for 16 weeks

Jeziorek M, Szuba A, Kujawa K, Regulska-Ilow B. The Effect of a Low-Carbohydrate, High-Fat Diet versus Moderate-Carbohydrate and Fat Diet on Body Composition in Patients with Lipedema. Diabetes Metab Syndr Obes. 2022 Aug 22;15:2545-2561

Keto and Lipedema Study #2

Poland Study

Parameter	Keto	Moderate Carb
Weight	-8.2 +/- 4.1 kg	-2.1 +/-1.0 kg
Lean body mass	-1.8 +/-0.9 kg	-0.6 +/- 0.3 kg
% Body Fat	-4.2 +/- 2/1%	-0.9 +/- 0.5%
Waist Circumference	-7.8 +/- 3.9 cm	-2.3 +/- 1/1 cm
Hip Circumference	-7.4 +/- 3.7 cm	-2.5 +/- 1/3 cm
Left Thigh Circumference	-4.9 +/- 2.4 cm	-1.3 +/- 0.6 cm

- The keto group also improved pain, swelling, mobility and quality of life
- It is unclear from the write-up how much these improved in the moderate carb group or how it compared between the two groups

Jeziorek M, Szuba A, Kujawa K, Regulska-Ilow B. The Effect of a Low-Carbohydrate, High-Fat Diet versus Moderate-Carbohydrate and Fat Diet on Body Composition in Patients with Lipedema. Diabetes Metab Syndr Obes. 2022 Aug 22;15:2545-2561

Clinician Bottom Line

Listen to clients for keys like:

- No matter what I do I can't lose weight from this area
- I'm a different size on top then on bottom
- My legs hurt all the time
- My legs bruise easily
- I can't tolerate massage/cat/baby on my lap
- My legs have always been big, even when I was a kid
- Some women in my family have legs like this
- I have fibromyalgia-like pain but negative for fibromyalgia

Interdisciplinary Approach

Consider lipedema and ask appropriate questions

Refer to vascular doctor, certified lymphedema therapist, psychological support, exercise specialist, social worker, dietitian and others

Consider other co-morbidities and refer appropriately e.g. PCOS, Ehlers Danlos Syndrome, venous insufficiency, eating disorder

Be sensitive to the risk that these individuals likely have years of medical mismanagement and likely medical trauma

Diet for Lipedema Summary

- Body weight
  - It is possible to lose non-lippy fat
  - Some researchers also report loss of lipedema fat
- Protein
  - Despite size, under-nutrition is still possible
  - Appropriate protein to match exercise needs
- Anti-inflammatory
  - Appears to provide pain relief
- Keto diet
  - Evidence of pain relief with a modified keto diet – anti-inflammatory version
- RAD diet
  - No published evidence and it may be overly restrictive
- Paleo diet
  - No published evidence – would need to be anti-inflammatory
- Elimination diet
  - Could be useful to identify food triggers contributing to pain and swelling

Case Studies

Case Study #1

Brenda

- 60-year-old female
- Ovarian cancer with lymphonodectomy
- Some lymphedema noticeable in early years
- Toe injury that got infected
- Then huge increase in lymphedema in both legs but one worse than the other
- Seeing lymphedema therapist for bandaging, MLD and education
- Some success with weight loss on her own but then plateaued
- Excellent records – My Fitness Pal and daily measurements

Case Study #1 Continued

Started 1:1 dietitian sessions

- Examined food records on high measurement days
- Revealed higher sodium intake
- Education on sources of sodium in the diet and alternatives
- Implemented low sodium strategies
- Making more food from scratch

Results

- Significant improvement in lymphedema measurements
- Weight loss ~ 20 lbs.
- New smaller compression

Bottom Line

- Some people are very salt sensitive
- Tracking is helpful in and of itself but, taking the time to look at your records and troubleshoot is next level

Case Study #2

Cecile

- 70-year-old female
- Primary lymphedema everywhere including trunk
- Fluid is now affecting her breathing
- Reports she has tried every diet during childhood and adulthood, without relief, only getting worse
- Doing MLD but bandaging legs only moves fluid into her trunk and belly

Case Study #2 Continued

Started with dietitian

- Learned about the lymphatic system and its role in fat digestion
- Client trialed low fat diet
- Introduced MCT oil
- Reported weight loss (due to widespread lymphedema, her weight is good indication of fluid status)
- Reports this is the only diet strategy where she has noticed any improvement in her lymphedema

Bottom Line

- Be open to learning and trying new things
- Even systemic, longstanding primary lymphedema can be impacted by diet

Case Study #3

Donna

- 30 years old
- Had large legs since childhood
- Was put on diets by her mother, which didn't help
- This began unhealthy relationship with food and diets
- Doctors did not recognize or diagnosis the condition
- Client discovered the words "lymphedema" and "lipedema" when doing social media searches on body positivity
- Worked through various medical professionals to finally get diagnosed and see a certified lymphedema therapist
- Multilayer compression bandaging and MLD with lifechanging results
- Doctor prescribed ketogenic diet…but client had no gallbladder – very sick

Case Study #3 Continued

Referral to dietitian

- Began anti-inflammatory diet

Results

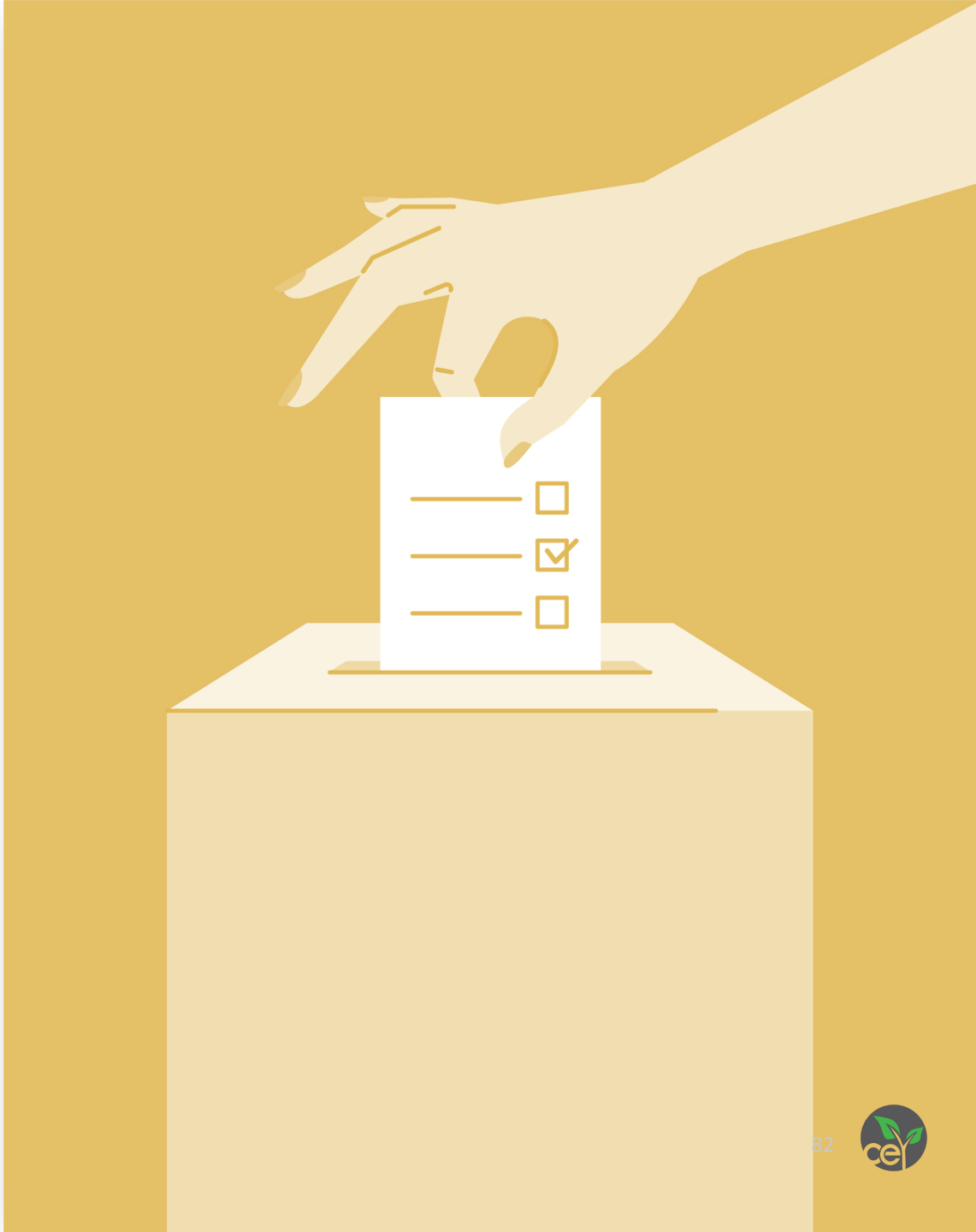
- Loss of weight
- Pain reduction from lipedema
- Lymphedema reduction
- Feels this is a lifestyle and not a diet
- Feels she can continue

Bottom Line

- Diet is not a one-size fits all
- Even if you have lipedema or lipo-lymphedema, weight loss is still possible
- Overcoming unhealthy relationship to food and eating is possible

Poll Questions

1. Can you recognize lymphedema?
2. Can you recognize lipedema?
3. Do you know the difference between lipedema, lymphedema and obesity?



Lymphedema vs Lipedema Summary

Lymphedema	Lipedema	Similarities
Men and women	Predominantly women	Genetic component
Primary and secondary	Primary only	Progressive
Not symmetrical	Symmetrical	Fibrotic fatty tissue
Can occur anywhere	Predominantly thighs, buttocks, legs, arms	Responds to CDT
Includes hands and feet	Doesn’t include hands and feet usually	Responds to anti-inflammatory diet, high fluid, low salt
Pitting edema (in early stages)	Non-pitting	Can occur together
		Has significant impact on quality of life

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Take Aways for Patients with Lymphedema and Lipedema

1. What you eat matters
2. When you eat matters
3. How much you eat matters

What would you do to build interdisciplinary relationships with other health care team members to improve care and advance learning for lipedema and lymphedema patients?

Post in the chat, let's share.

What are the barriers to building interdisciplinary relationships with other disciplines on the healthcare team?

Post in the chat, let's share.

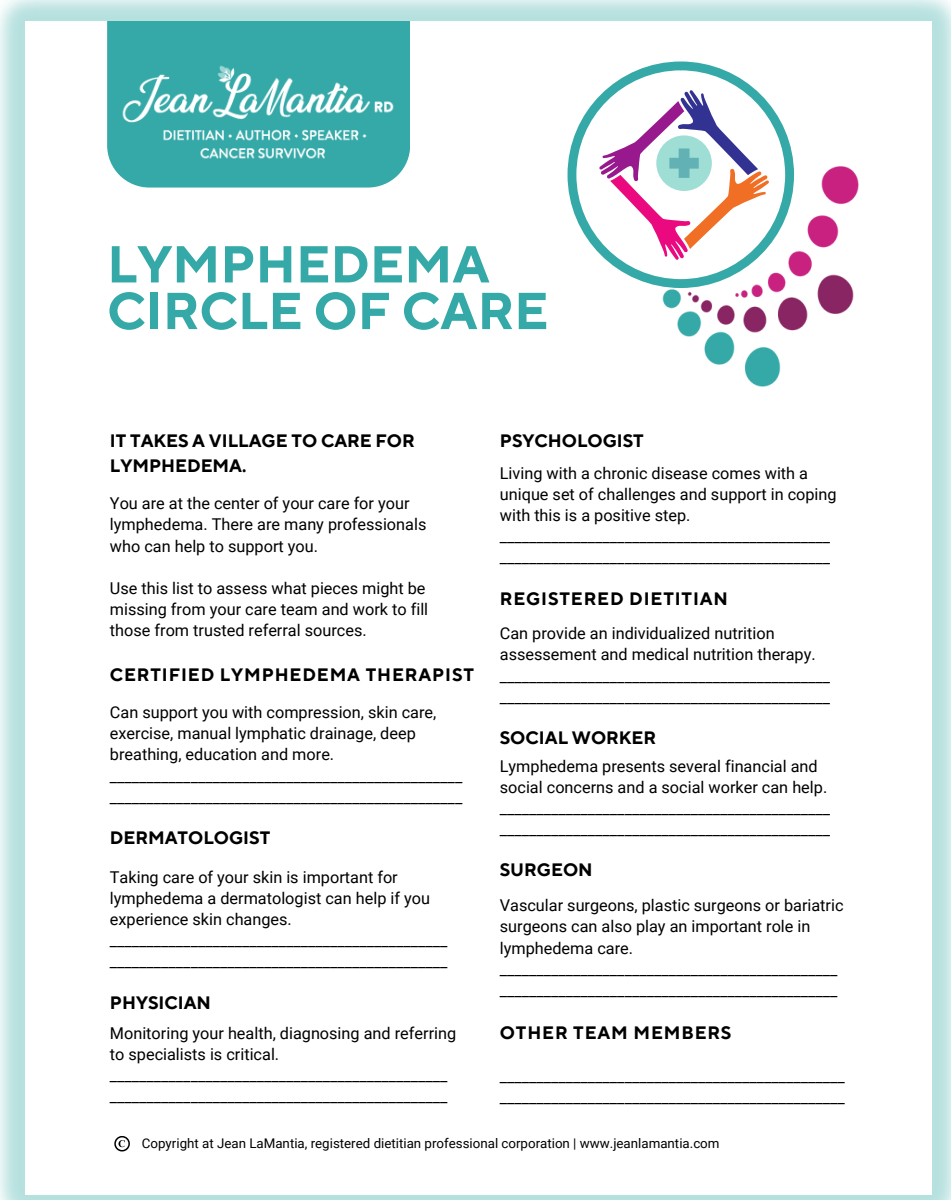
Let's Share Our Strategies….

What are some strategies you have implemented that have helped to remove or address challenges in team-based approach to care?

Post in the Chat. Your Answers will be compiled and shared as a handout after the event.

Multidisciplinary Approach

- Certified Lymphedema Therapist
- Dermatologist
- Physician
- Psychologist
- Registered Dietitian
- Social Worker
- Surgeon
- Others



Jean LaMantia RD
DIETITIAN • AUTHOR • SPEAKER • CANCER SURVIVOR

LYMPHEDEMA CIRCLE OF CARE

IT TAKES A VILLAGE TO CARE FOR LYMPHEDEMA.

You are at the center of your care for your lymphedema. There are many professionals who can help to support you.

Use this list to assess what pieces might be missing from your care team and work to fill those from trusted referral sources.

CERTIFIED LYMPHEDEMA THERAPIST

Can support you with compression, skin care, exercise, manual lymphatic drainage, deep breathing, education and more.

DERMATOLOGIST

Taking care of your skin is important for lymphedema a dermatologist can help if you experience skin changes.

PHYSICIAN

Monitoring your health, diagnosing and referring to specialists is critical.

PSYCHOLOGIST

Living with a chronic disease comes with a unique set of challenges and support in coping with this is a positive step.

REGISTERED DIETITIAN

Can provide an individualized nutrition assessement and medical nutrition therapy.

SOCIAL WORKER

Lymphedema presents several financial and social concerns and a social worker can help.

SURGEON

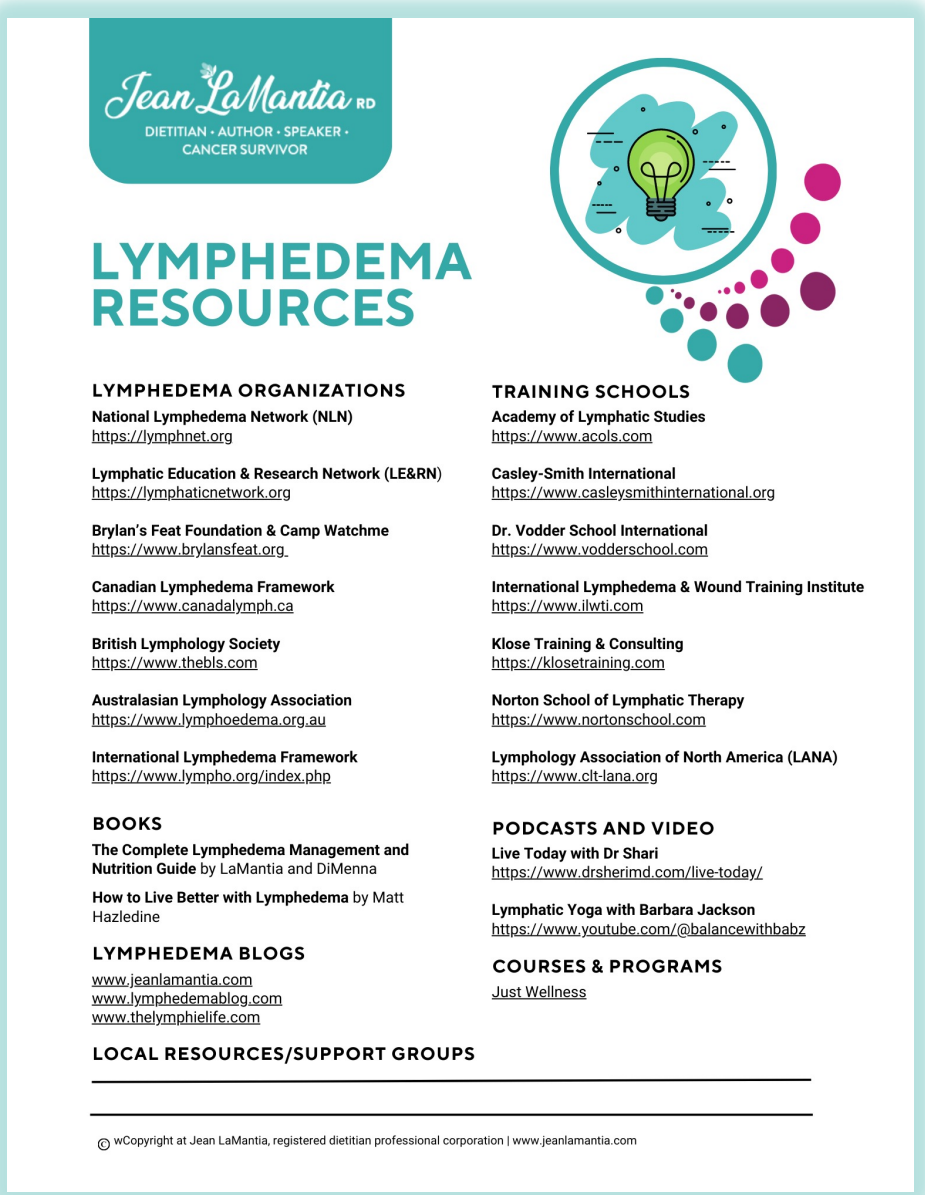
Vascular surgeons, plastic surgeons or bariatric surgeons can also play an important role in lymphedema care.

OTHER TEAM MEMBERS

Resources

- www.fatdisorders.org
- www.jeanlamantia.com
- https://www.lymphcareusa.com
- https://lymphaticnetwork.org
- http://www.curelipedema.org
- http://www.lipomadoc.org
- http://www.lipomadoc.org

- Free downloads at www.jeanlamantia.com



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LYMPHEDEMA RESOURCES

LYMPHEDEMA ORGANIZATIONS

National Lymphedema Network (NLN)
https://lymphnet.org

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

Brylan's Feat Foundation & Camp Watchme
https://www.brylansfeat.org

Canadian Lymphedema Framework
https://www.canadalymph.ca

British Lymphology Society
https://www.thebls.com

Australasian Lymphology Association
https://www.lymphoedema.org.au

International Lymphedema Framework
https://www.lympho.org/index.php

TRAINING SCHOOLS

Academy of Lymphatic Studies
https://www.acols.com

Casley-Smith International
https://www.casleysmithinternational.org

Dr. Vodder School International
https://www.vodderschool.com

International Lymphedema & Wound Training Institute
https://www.ilwti.com

Klose Training & Consulting
https://klosetraining.com

Norton School of Lymphatic Therapy
https://www.nortonschool.com

Lymphology Association of North America (LANA)
https://www.clt-lana.org

BOOKS

The Complete Lymphedema Management and Nutrition Guide by LaMantia and DiMenna

How to Live Better with Lymphedema by Matt Hazledine

PODCASTS AND VIDEO

Live Today with Dr Shari
https://www.drsherimd.com/live-today/

Lymphatic Yoga with Barbara Jackson
https://www.youtube.com/@balancewithbabz

LYMPHEDEMA BLOGS

www.jeanlamantia.com
www.lymphedemablog.com
www.thelymphielife.com

COURSES & PROGRAMS

Just Wellness

LOCAL RESOURCES/SUPPORT GROUPS

Questions?

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