In Support of Lymphedema Risk Reduction Behaviors

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BROWN UNIVERSITY, ALPERT MEDICAL SCHOOL
Objectives

- Review Lymphedema Risk Reduction Behaviors: medical interventions and patient behaviors
- Review limitations of evidence in a clinically defined disease
- Expand beyond BCRL (try)
- Propose truly informed decision making
I have lymphedema
I was told not to worry
I had no identifiable risk factors
I had a significant knowledge deficit (so did my providers)
My initial treatment from PT and breast surgeon may have made my clinical situation worse
Lymphedema was not on any consent form—surgery or radiation
I subsequently worked in a radiation oncology practice and saw undiagnosed lymphedema daily
Embrace uncertainty

- Lymphedema is a clinical diagnosis—some body areas are impossible to measure
- The evidence will be influenced by arbitrary definitions
- Lymphedema is a dynamic process
- Lymphedema has variable onset
- Lymphedema risk factors are not completely known and may be not easily measurable or modifiable: genetic risk, inherent vigor of the lymphatic system
- Unknowable—all of the inherent risks for lymphedema, currently
Medical knowledge is evolving

- The American College of Surgeons Oncology Group Z0011 trial--initial report on survival and subsequent report on local recurrence.

- “The finding that axillary lymph nodes with metastases do not require resection is disturbing to surgeons. However, the history of breast cancer management has revealed that our preconceptions concerning the extent of operation necessary to achieve cure for patients with early breast cancer have often been excessive.”
“I had been cancer free for almost 8 1/2 years. I had flown on planes I’ve had many surgeries and never a problem with lymphedema. Honestly, no one ever mentioned lymphedema. I didn’t even know what it was. Now thinking back on it, I had 14 lymph nodes removed, chemo, 27 rounds of radiation, three long surgeries to complete my breast reconstruction. “

“That day 8 1/2 years later I got a blood draw in my right arm which lasted about 10 seconds. The next day I was diagnosed with lymphedema and was finally educated on what that even was and I just about fell over when I found out that this is for the rest of my life. I was pretty much out of the danger zone for getting lymphedema. “

“Then above all else the nurse wasn’t honest about what happened.”
Healthy Habits for Patients at Risk for Lymphedema

Healthy Lifestyle:
A healthy diet and exercise are important for overall good health.
- Maintain optimal weight through a healthy diet and exercise to significantly lower the risk of lymphedema.
- Gradually build up the duration and intensity of any activity or exercise. Review the Exercise Position Paper.*
- Take frequent rest periods during activity to allow for recovery.
- Monitor the at-risk area during and after activity for change in size, shape, tissue texture, soreness, heaviness, or firmness.

Skin Care:
Make sure that your skin is in good condition.
- Keep your at-risk body part clean and dry.
- Apply moisturizer daily to prevent chapping/chafing of skin.
- Pay attention to nail care and do not cut cuticles.
- Protect exposed skin with sunscreen and insect repellent.
- Use care with razors to avoid nicks and skin irritation.

Medical Check-ups:
Find a certified lymphedema therapist (CLT).*
- Review your individual situation, get screened for lymphedema, and discuss risk factors with your CLT.
- Ask your CLT or healthcare professional if compression garments for air travel and strenuous activity are appropriate for you.
- If a compression garment is recommended, make sure it is properly fitted and you understand the wear, care, and replacement guidelines.
- Set a follow-up schedule based on your needs with your CLT.
- Report any changes in your at-risk body part to your CLT.

Infection Education:
Know the signs of infection and what to do if you suspect you have one.
- Signs of infection: rash, itching, redness, pain, increased skin temperature, increased swelling, fever, or flu-like symptoms.
- If any of these symptoms occur, contact your healthcare professional immediately for early treatment of possible infection.
- If a scratch or puncture to your skin occurs, wash it with soap and water, apply topical antibiotics, and observe for signs of infection.
- Keep a small first aid kit with you when traveling.

TRY TO AVOID POSSIBLE TRIGGERS

Injury or Trauma
- Wear gloves while doing activities that may cause skin injury (e.g., washing dishes, gardening, using chemicals like detergent).
- Try to avoid punctures (e.g., injections and blood draws).

Limb Constriction
- Wear loose jewelry and clothing.
- Avoid carrying a heavy bag or purse over the at-risk limb.
- Try to avoid blood pressure cuffs on the at-risk limb.

Extreme Temperatures
- Avoid exposure to extreme cold, which can cause rebound swelling or chapping of skin.
- Avoid prolonged (> 15 min.) exposure to heat, particularly hot tubs and saunas.

Prolonged Inactivity
At-risk for leg lymphedema?
- Avoid prolonged standing or sitting by moving and changing position throughout the day.
- Wear properly fitted footwear and hose.
“Please Note: These guidelines are meant to help reduce your risk of developing lymphedema and are NOT prevention guidelines.

Because there is little research about risk reduction, many of these use a common-sense approach based on the body’s anatomy and knowledge gained from decades of clinical experience by experts in the field. Risk reduction should always be individualized by a certified lymphedema therapist and healthcare professional. “

I personally don’t find any of these guidelines controversial or burdensome

Except, maybe, for the healthcare system
Any definition based on measurement of volume/swelling is inherently arbitrary

“There is no one value or standard you can use to say, ‘OK, if you meet that you have lymphedema, and if you don’t, well then you don’t have it,’” Andrea Cheville, https://www.breastcancer.org/treatment/lymphedema/evaluation/diagnosis

“We are addicted to objectification and parameterization in medicine, so it never seems to stick.”
<table>
<thead>
<tr>
<th>Stage</th>
<th>International Society of Lymphology</th>
<th>American Physical Therapy Association</th>
<th>NCI-CTCAE Grade</th>
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</thead>
<tbody>
<tr>
<td>0</td>
<td>Subclinical swelling not apparent on clinical exam despite impaired lymph flow</td>
<td>Mild: Maximum girth difference between the affected and unaffected limb of less than 3 cm</td>
<td>Grade 1: Trace thickening or faint discoloration</td>
</tr>
<tr>
<td>1</td>
<td>Soft edema that pits with no dermal fibrosis and subsides with limb elevation within 24 hours.</td>
<td>Moderate: Maximum girth difference between the affected and unaffected limb between 3-5 cm</td>
<td>Grade 2: Marked discoloration, leathery skin texture, and papillary formation that limit IADLs</td>
</tr>
<tr>
<td>2</td>
<td>Nonpitting lymphedema that does not resolve with limb elevation, reflecting evolution of dermal fibrosis</td>
<td>Severe: Maximum girth difference between the affected and unaffected limb greater than 5 cm</td>
<td>Grade 3: Severe symptoms that limit self-care and ADLs</td>
</tr>
<tr>
<td>3</td>
<td>Lymphostatic elephantiasis with nonpitting edema with skin changes of acanthosis and warty overgrowths</td>
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</tbody>
</table>
Don’t rely on volume: clinical exam is essential, as is history

Diagnosing breast cancer-related lymphoedema in the arm

Anthony Stanton, Stephanie Modi, Russell Mellor, Rodney Levick, Peter Mortimer
"Measurement of arm volume is of little value in detecting early, mild BCRL and reliance on comparison of arm volumes or circumferences will cause an underestimation of the prevalence"

Odema can be very focal—in one patient, just her thumb
This is Lymphedema

Looks pretty normal

Note the MCP abnormality
Not just BCRL

- I’ve diagnosed lymphedema in
- 1) multiple myeloma
- 2) lung cancer
- 3) head and neck cancer
- 4) cervical cancer
- 5) prostate cancer
- 6) vulvar cancer
- 7) hemi-colectomy
- 8) obesity
- 9) primary
Primary Prevention

- **Primary prevention** aims to prevent disease or injury before it ever occurs.
- the provision of information on behavioral and medical health risks
- WHO
Secondary prevention aims to reduce the impact of a disease or injury that has already occurred.

- This is done by detecting and treating disease or injury as soon as possible to halt or slow its progress, encouraging personal strategies to prevent re-injury or recurrence.
- Control disease progression.
Tertiary Prevention

- **Tertiary prevention** aims to soften the impact of an ongoing illness or injury that has lasting effects.
Preoperative Lymphedema-Related Risk Factors in Early-Stage Breast Cancer

Zeynep Erdogan Iyigun, MD,1 Tomris Duymaz, PT,1 Ahmet Serkan Ilgun, MD,2 Gul Alco, MD,3 Cetin Ordu, MD,4 Dauren Sarsenov, MD,5 Ayse Esra Aydin, MD,5 Filiz Elbukan Celebi, MD,6 Filiz Izcı, MD,7 Yeşim Eralp, MD,3 and Vehit Ozmen, MD9
A total of 277 patients who were diagnosed as having breast cancer, were planned to undergo a surgical intervention, and had no clinical lymphedema were included in the study. The presence of lymphedema was evaluated with clinical examination, measurement of arm circumference, and bioimpedance analysis.

Lymphedema was found in 59 (21.3%) patients with no detected differences in arm circumferences.

Preoperative bioimpedance analysis demonstrated that 1/5 of the patients had subclinical lymphedema. Preoperative subclinical lymphedema is associated with obesity and the number of positive lymph nodes.
Number Needed to Harm/Number needed to treat
The Debunking Debate
Impact of Ipsilateral Blood Draws, Injections, Blood Pressure Measurements, and Air Travel on the Risk of Lymphedema for Patients Treated for Breast Cancer

Chantal M. Ferguson, Meyha N. Swaroop, Nora Horick, Melissa N. Skolny, Cynthia L. Miller, Lasren S. Jammallo, Cheryl Brunelle, Jean A. O'Toole, Laura Salama, Michelle C. Spechi, and Alphonse G. Tighian
“This study suggests that although cellulitis increases risk of lymphedema, ipsilateral blood draws, injections, blood pressure readings, and air travel may not be associated with arm volume increases. “

“The results may help to educate clinicians and patients on post-treatment risk, prevention, and management of lymphedema.”
Although we cannot affirmatively state that risk-reduction practices have no effect on arm swelling, we hope to generate evidence that brings reasonable doubt to burdensome guidelines and encourage further investigation into non-precautionary behaviors and the risk of lymphedema.

“Patients in our cohort do not routinely receive recommendations to avoid blood draws, injections, or blood pressure readings or to wear a compressive sleeve while flying.”

Think about the clinical vignette/patient experience—is this a relief?
“Study debunks conventional guidance about lymphedema prevention.” 3/11/16

“This important study debunks conventional guidance that blood draws, injections, BP assessment, and air travel raise risk for lymphedema in a low-risk population.”
Commonly Cited Lymphedema Risk Factors ‘Myth-busted’

All these recommendations are anecdotally based. None withstood formal evaluation in a prospective study of 710 breast cancer patients with 860 treated and thus potentially at-risk breasts, Chantal M. Ferguson reported at the San Antonio Breast Cancer Symposium.

Practice Update: 1/28/15 Frontline Medical News, Oncology, SABC
“I’m not sure that we can take these data to say we can let patients go hog wild and get their blood pressure measured all the time on that arm. This is a large prospective trial featuring a broad range of patient ages and BMIs, and both lumpectomy and mastectomy patients, and the trial adds a lot to the literature, but it does need to be interpreted with caution."

“Few medical oncologists are well informed about lymphedema or the numerous and highly complex functions of the lymphatic system”

Dr. Michelle E. Melisko, Oncologist USCF
“Lymphedema Precautions: Time to Abandon Old Practices? Ahn and Port

“Only weight gain and infections have been shown to be true risk factors for developing lymphedema.”

“As for other preventative behaviors, patients should be informed that there are not enough data to justify recommending strict adherence to avoiding skin punctures, blood pressure measurements, or use of compressive garments for air travel.”
### Table 2. Recommendations for Patients After Axillary Surgery

<table>
<thead>
<tr>
<th>Evidence-Based Recommendations</th>
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<tbody>
<tr>
<td>To avoid weight gain</td>
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<tr>
<td>Regular exercise</td>
</tr>
<tr>
<td>Healthy diet</td>
</tr>
<tr>
<td>To avoid infection</td>
</tr>
<tr>
<td>Timely first aid</td>
</tr>
<tr>
<td>Immediate identification and treatment of infection</td>
</tr>
<tr>
<td>Skin care</td>
</tr>
<tr>
<td>Continue</td>
</tr>
<tr>
<td>Air travel</td>
</tr>
<tr>
<td>Blood pressure measurements</td>
</tr>
<tr>
<td>Exercise</td>
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Table 2. Recommendations for Patients After Axillary Surgery
MGH has a large number of Bilateral at Risk Women

In our hospital, the majority of patients who chose to undergo contralateral prophylactic mastectomy undergo sentinel lymph node biopsy on their unaffected breast to stage an occult breast cancer if discovered on final pathology.
Sentinel lymph node biopsy at the time of mastectomy does not increase the risk of lymphedema: implications for prophylactic surgery

Cynthia L. Miller · Michelle C. Specht · Melissa N. Skolny · Lauren S. Jammallo · Nora Horick · Jean O’Toole · Suzanne B. Coopey · Kevin Hughes · Michele Gadd · Barbara L. Smith · Alphonse G. Taghian
Findings from that Study

- “Although it was not found to be of statistical significance in this analysis, our data suggests a trend toward increased lymphedema symptoms reported by patients with SLNB compared to those without axillary surgery.”

- Incidence of occult cancer varies: meta-analysis 1.7%

- 3 (2.8%) patients had invasive cancer and 1 micrometastasis—prophylactic side

- Argued that SLNB cost effective vs. staging breast MRI

- “In conclusion, we have demonstrated that the addition of SLNB to mastectomy does not significantly increase the risk of lymphedema.”
Common Goals

What is best possible outcome for patients?

1) Survival—and survivorship
2) Minimal morbidity
3) Therapeutic alliance

Patient education—recurring theme :"I had no idea." “My doctors didn’t tell me.”

Provider education and treatment modification
Risk Factors

- Obesity
- Infection/cellulitis
- Surgery or other trauma
- Radiation
- Chemotherapy
- Inherent vigor of lymphatic system
- Genetic predisposition
- Seroma
- Metastasis in lymph nodes
- Cording?
- Unknown
Identification and Management of Lymphedema in Patients With Breast Cancer

Pavankumar Tandra, MBBS¹; Ayyaka Kallam, MD¹; and Jairam Krishnamurthy, MBBS¹
Risk factors for BCRL can be host related or therapy related—axillary surgery with or without axillary radiation, postoperative infections, seroma or hematoma, chemotherapy with taxanes, and obesity.

- BCRL can present immediately or as late as 30 years after ALND
- Obesity raises the risk by a factor of 30x
- Best proposed practices: early identification, early referral and patient education about skin care, nail care and obesity
- They agree that definition is arbitrary and doesn’t include areas of the quadrant at risk that are not easily measurable
Their algorithm to prevent BCLR

- **Upfront lumpectomy**
  - Can we avoid SLNB altogether?†
  - Can we avoid whole-breast radiation?†

- **Upfront mastectomy**
  - Can we perform SLND and can we avoid cALND if SLND is positive?*'
  - Can we avoid postmastectomy chest wall or nodal radiation?#

- **Upfront chemotherapy**
  - Can we perform SLND after NACT and can we avoid cALND if SLND is positive?¶
  - Can we perform TAD?¶
  - Can we avoid/minimize nodal radiation if patient achieves pCR#

MDC evaluation

Avoid weight gain (with healthy diet and exercise) and infection (with skin and nail care and timely antibiotics)

Prefer the unaffected arm for BP measurements, injections, and phlebotomy, if possible
Janice Cormier: “I don’t treat lymphedema—I cause it.” “Handle the tissues with care.”

“The finding that axillary lymph nodes with metastases do not require resection is disturbing to surgeons.”

Personal experience, some surgeons had lower incidence of lymphedema. Cosmesis did not equate with incidence of lymphedema—oncoplastic breast surgery involves tissue disruption.

Direct disruption of lymphatic system: lymphadenectomy, scars, seroma, cording.
Lymphadenectomy necessary?

- ACOSOG Z0011 trial—ALND did not convey survival or recurrence benefit in women with T1-T2 cancers and clinically negative nodes
- NEJM, 2/19, A Randomized Trial of Lymphadenectomy in Patients with Advanced Ovarian Neoplasms: if clinically normal nodes, removal did confer benefit
- SLN identification is still experimental in prostate cancer
- Lymphadenectomy for the management of endometrial cancer, Cochrane review 2010, no benefit for stage I disease—reviewed 2017, still no benefit
Risk Associated with Lymphadectomy

- Higher risk of lymphedema with more lymph nodes taken.
- Seroma confers risk of lymphedema: Breast 2017, “Seroma indicates increased risk of lymphedema following breast cancer treatment: A retrospective cohort study”.
- Seroma doubled the risk of lymphedema—"Future studies should examine if seroma reducing measures will lead to lower risk of lymphedema.”
- Other risk factors were: lymphadenectomy, radiation therapy, chemotherapy, BMI above 30, total lymph nodes removed above 15 and higher number of metastatic lymph nodes.
Advice to Patients

- Discuss lymph node sampling plans with surgeon, clarify the consent form, have nodes evaluated pre-operatively if possible.

- Breast cancer patients: limit stretch through axilla for 7-10 days, inform surgeon of any seroma formation (clinical advice, also supported by negative impact of seroma.)

- All patients who have had lymph nodes removed: be aware of infection, seroma formation and get basic information on lymphedema to allow for symptom monitoring.
Incidental radiation to axilla in early breast cancer treated with intensity modulated tangents and comparison with conventional and 3D conformal tangents. Kataria T, Breast. 2013

Whole breast radiation delivers a significant dose to the axilla

Axillary levels I and II received substantial amount of incidental radiation by all the three techniques

The treating oncologist may choose to give constraints to axilla if lymphedema is a concern
Figure 3. Comparison of dose-volume histograms for each level of the axilla between the 3D-CRT and IMRT plans. 3D-CRT, 3-dimensional conformal radiotherapy; IMRT, intensity-modulated radiotherapy.
Advice to Patients

- The lymphatic system is harmed by radiation.

- Discuss your radiation plan with your radiation oncologist: will the radiation be delivered by IMRT? Can I see the dose histograms? What dose and how many fractions? For breast cancer patients—"what are the tangents? Are they close to the top of my humerus? Why?"
Nomograms for Predicting the Risk of Arm Lymphedema after Axillary Dissection in Breast Cancer
Genetic predisposition


- Associations between genetic factors and the development of secondary lymphedema were found for variations in HGF, MET, GJC2, IL1A, IL4, IL6, IL10, IL13, VEGF-C, NFKB2, LCP-2, NRP-2, SYK, VCAM1, FOXC2, VEGFR2, VEGFR3, and RORC.

- In patients with secondary lymphedema following breast cancer therapy, genetic variations were found in 18 genes. These compelling, although preliminary, findings may suggest a possible role for genetic predisposition in the development of lymphedema following breast cancer therapy. This notion may add to the classical, more mechanistic explanation of secondary lymphedema.
Connexin 47 Mutations Increase Risk for Secondary Lymphedema Following Breast Cancer Treatment

David N. Finegold, Catherine J. Baty, Kelly Z. Knickelbein, Shelley Perschke, Sarah E. Noon, Diana Campbell, Jenny M. Karlsson, Diana Huang, Mark A. Kimak, Elizabeth C. Lawrence, Eleanor Feingold, Stephen D. Meriney, Adam M. Bufsky, and Robert E. Ferrell

DOI: 10.1158/1078-0432.CCR-11-2303 Published April 2012
How do we add Genetic predisposition to Risk counseling

- Potential questionnaire
- Family history
- If I can order genetic testing for my dog or myself inexpensively, why isn’t it available for lymphedema?
Dogs large and small, part of something big

Every dog in our database brings us closer to realizing our mission of ending preventable disease in dogs. Our decision to develop a proprietary research-grade DNA genotyping platform at Cornell University College of Veterinary Medicine was rooted in establishing technology that enabled us to have the greatest potential to make future genetic discoveries.
Constitutively Enhanced Lymphatic Pumping in the Upper Limbs of Women Who Later Develop Breast Cancer-Related Lymphedema

Viviana Cintolesi, BSc, Anthony W.B. Stanton, MB BCh, PhD, Salana K. Bains, MRCS, PhD,
Emma Cousins, BSc, A. Michael Peters, MD, FRCR, FRCPath, FRCP, MSc,
Arnie D. Purushotham, MD, FRCS, J. Rodney Levick, DSc, DPhil, BM BCh, MA,
and Peter S. Mortimer, MD, FRCP.
Conclusions

- Conclusions: Women destined to develop BCRL have higher pumping pressures and lymph transport, indicating harder-working lymphatics before cancer treatment.

- Axillary lymphatic damage from surgery appears to compromise lymph drainage in those women constitutively predisposed to higher lymphatic pressures and lymph transport.
Conclusions: Women destined to develop BCRL have higher pumping pressures and lymph transport, indicating harder-working lymphatics before cancer treatment. Axillary lymphatic damage from surgery appears to compromise lymph drainage in those women constitutively predisposed to higher lymphatic pressures and lymph transport.

Pump failure can also offer a rational explanation for the regionality paradox; if the constitutionally weakest lymphatic collector vessels fail first, swelling will be localized to their drainage territory, that is, hand, forearm, or upper arm.
Avoidance of Trauma

“We do have an exceptional amount of anecdotal evidence, that aligns with understood physiological responses in a common sensical manner.

trauma = increase in inflammation = increase fluid load = increase risk for swelling if someone has an impaired ability to manage fluid load

There is a strong physiological basis that supports this as a common sense approach.”

Nicole Stout PT, DPT, FAPT, CLT-LANA
Periods of increased risk?

- 47% (21 of 45) of cellulitis episodes occurred in the immediate postoperative period and therefore before the first postoperative arm measurement.

- Many of my patients took a vacation after radiation, with swollen, burned skin—many developed cellulitis.

- If cording is present.

- As the lymphatic system fatigues.
Myth?
Avoid Iatrogenic Trauma

- Blood pressure: careful manual vs. repeated automatic cuff
- Blood draw: careful butterfly vs. large hematoma
- Intravenous infusion: can cause phlebitis, infection
Data is poor quality

Poorly fitting compression or incomplete compression may trap fluid
Exercise

- Resistance Exercise in BCRL appears to be safe and may confer benefits

- **Resistance exercise and breast cancer related lymphedema - a systematic review update, 1/19, Disability and Rehabilitation, Hasenoehri, et al**

- Lymphedema assessment was so heterogeneous that conduction of a thorough meta-analysis regarding lymphedema status was still impossible

- RE seems to be a safe exercise intervention for BCS and not to be harmful concerning the risk of lymphedema
Recent google alert for lymphedema:

“First, let's dispel the myths that come along with exercise and cancer. One of the most common myths is that exercise leads to lymphedema.”

“The myth is that exercise damages axillary lymphatics resulting in poor lymph flow; however, the fact is that vigorous, upper body exercise is not related to total arm volume. Lymphatic clearance is higher in endurance-trained athletes due to an increase in capillary density.”
Proposed Exercise
Hold Plank for 10 Seconds to 2 Minutes
True Informed Decision Making

Note tendons and knuckles on left hand are not visible. Skin is tight and less mobile on back of hand.

Tendons, knuckles and blood vessels are visible on right Non-LE hand. Skin is wrinkly and easily moved.
Spaces between knuckles on Left hand are puffy. No tendons visible. Note shiny appearance of swelling on back of hand. Less wrinkles at wrist area

Knuckles, tendons, blood vessels on Right Non-LE hand are visible. Skin wrinkles more apparent. Skin is easily moved or pinched.
Note the straight edge line formed by tops of knuckles when making a fist. Edema in the hand and fingers prevents full closure of the left hand. Veins not as visible in forearm.

Knuckles in closed fist create a slanting line. Less congestion in the hand and fingers allows for tighter closing of fist. Tendons and veins are visible in forearm.
Left thumb can only reach mid palm due to extra congestion in base of thumb and palmar area. Movement is constricted by swelling in tissues around the joints.

Right thumb is more flexible and can reach towards pinky finger. Palm area is looser, more concave with less constriction around joints.
When attempting to do the Boy scout handsign I can barely touch my pinky with my left thumb and can’t keep my ring finger straight.

I can easily touch the second joint of my pinky with my right thumb and still keep my other fingers straight.
Left Hand profile is much thicker compared to the right. Note the puffiness on palm at metacarpals. Tendons on back of hand cannot be easily felt.

Right hand profile is slimmer than left. No puffiness at metacarpals. Tendons on back of hand can easily be felt.
Note that left elbow is not as sharply defined as the right elbow. Bony prominences may be harder to see when LE swelling is present. Left upper arm is fuller than right upper arm.

Right elbow bone can be seen and easily felt around all margins. Right upper arm has better muscle definition and less fullness than left arm.
Linda

- Bilaterally at risk, chose to use her "non-LE" arm for medical procedures
- Highly educated, health care professional
- Dedicated to education and support
- Did develop overt lymphedema bilaterally
- Educating as she dealt with progressive disease: had the hospital put an alert in EPIC about the rate of contrast infusion to avoid extravasation and issues around power port
“My takeaway lesson from learning to deal with Advanced Cancer and lymphedema is you MUST make fighting the cancer the priority.”

“It does not need to be an either/or situation, but rather a comprehensive approach that will first address the cancer treatment needs and then effectively deal with any secondary lymphedema issues.”
“In the treatment community, we’re talking more about the importance of developing a risk profile for every patient,” says Nicole Stout, MPT, CLT-LANA,

“We must identify women at high risk and monitor them a little more closely for signs and symptoms and complications of lymphedema.

But we also have to realize there will always be those ‘outliers’ who appear to be low risk but still develop lymphedema.”

http://www.breastcancer.org/treatment/lymphedema/risk_factors
Have we proven that people with damaged lymphatic systems are at No Risk with trauma?

- No
- The tipping point will vary
- The timing will vary
- Recognition of disease is paramount
- Don’t “deny our reality
Why is Lymphedema under-recognized/Under-Treated

- Cognitive Dissonance
- Ego Dystonic—we don’t want to give patients incurable illness
- Sense of futility—treatment is hard to access and knowledge base is lacking
- No designated person—rehabilitation/primary/medical oncologist/surgeon/gynecologist? “Your lymphedema therapist can prescribe a sleeve”
- But is debunking lymphedema risk reduction practices in the best interest of patients?
- Who bears the burden? The healthcare system or the patients?
Cellulitis after Treatment for Breast Cancer

“no lymphedema was palpable”
Low risk = 100% when it happens to you
Evidence Based Medicine has Limitations

Many results that are rigorously proved and accepted start shrinking in later studies.

Illustration by LAURENT CILLUFFO
Knowledge is power and early diagnosis leads to best outcomes

Lymphedema is a clinical diagnosis and arbitrary volume definitions will miss disease—especially in body areas that can not be measured

Someone in the medical team needs to “own” lymphedema

Know the treatment options for lymphedema and how to identify sub-optimal treatment and barriers to treatment

Fear comes from the unknown, agency from understanding and having advocates and skilled treatment

Modify medical treatment if possible to avoid damage to lymphatics
Risk Reduction Practices for Health Care Providers

- Surgeons: avoid unnecessary trauma to the lymphatic system
- Radiation oncologists: plan radiation to avoid unnecessary exposure, and to reduce fibrosis
- All health care providers: learn how to recognize lymphedema and understand treatment
- Lymphedema is not only present in oncology patients
- Educate your patients, yourselves and any and all health care providers
Risk Reduction Practices for Patients

- High quality patient education: what is lymphedema, what increases risk, what increases lymphatic load
- Modify modifiable risks: avoid infection, obesity, trauma, overload of lymphatic system, inflammation and barriers to lymphatic flow
- Information on self evaluation
- Information on accessing treatment
- Skin care, nail care
- Avoid trauma to quadrant/area at risk
- Explain concerns about air travel
We Are Essentially in Agreement

- We want the best for our patients
- We want to empower our patients and provide the best care
- Any medical intervention involves a risk/reward analysis
- Medical knowledge is always evolving
- Over-simplification, nihilism, absolute certainty
- For me, it’s a no-brainer: inform, avoid unnecessary trauma, inform and empower and be available