

# WHAT WE NEED OUR DOCTORS, NURSES AND ALL OTHER HEALTHCARE PERSONNEL TO DO AND KNOW ABOUT LYMPHEDEMA

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TO OUR DOCTORS (SURGEONS, ONCOLOGISTS, PRIMARY CARE PHYSICIANS, GYNECOLOGISTS, AND OTHER PHYSICIANS)

PLEASE PROVIDE ALL OF YOUR BREAST CANCER PATIENTS WITH INFORMATION REGARDING LYMPHEDEMA!!

A recently published study showed that accurate patient education is a critical dimension of lymphedema risk-reduction. Knowledge of lymphedema and its risk reductions is essential to all breast cancer patients, and makes a difference in their long-term quality of life. In this study ***only fifty-seven percent of the participants reported that they received lymphedema information.***

- *"Cancer-Related Lymphedema: Information, Symptoms, and Risk-Reduction Behaviors,"* Authors: Fu, Mei R.; Axelrod, Deborah; Haber, Judith, Source: Journal of Nursing Scholarship, Volume 40, Number 4, December 2008 , pp. 341-348(8)

If you don't ask, you will not know when your breast cancer patients have lymphedema: ask routinely about arm heaviness, tingling, swelling, tightening or any other discomfort. A survey found that half of the patients acknowledging arm swelling in a mail questionnaire had never reported this problem to any doctor or other health care provider.

- *"Incidence of Breast Carcinoma-Related Lymphedema",* (Cancer Supplement 12/15/1998, Vol.83, #12 pp 2776-2781.)

If we appear stubborn, it is because we have had to be our own advocates for so long. Women and men trying to reduce their risk of lymphedema have been called uncooperative, difficult, silly, hysterical, and un-educated. We have been accused of over-reacting, and over-stating our risk. Most of us are battling cancer, and did not invite the additional risk of lymphedema as a consequence of our treatments. We certainly do not welcome or enjoy battling with our medical providers about lymphedema prevention. Although swelling of an arm or a chest wall might seem trivial in comparison to breast cancer, lymphedema is a painful, visible, expensive medical condition that increases our chance of developing a life-threatening infection. Our own individual risk might seem low to you (6-30%), but once lymphedema occurs, it cannot be cured. It can only be managed. We face a lifetime of limitations on strenuous physical activity, self-consciousness when wearing our lymphedema garments, expense associated with items not covered by our insurance or Medicare, and other difficulties too numerous to mention.

Please understand that we will do everything we can to minimize our risk, even if it means arguing with you.

We would never ask you to avoid using "universal precautions" such as protective gloves to protect yourselves and tell you your risk of getting AID's from us was "low." We understand your need to protect yourselves from a lifelong distressing, possibly fatal, disease. Please understand our same need to protect ourselves from developing lymphedema, a lifelong painful condition, if we are at risk, and from worsening our lymphedema, if we already have it.

1. Please include a lymphedema assessment, along with taking our weight and vital signs, during follow-up visits with breast cancer patients. Having measurements of arm circumference in our medical records will alert your staff to any subtle changes that might have occurred since the previous visit.
  
2. We ask that you refer all your breast cancer patients to a qualified lymphedema therapist for early assessment of their lymphedema risk. Ideally, this would be done prior to surgery, so that baseline measurements could be taken and kept on file in case a problem occurs later. An early consultation with a lymphedema therapist also provides an opportunity for educating your patients regarding lymphedema risk reduction.
  - *"Preoperative Assessment Enables Early Diagnosis and Successful Treatment of LE"* [Cancer, June 15, 2008, Volume 112, Number 12) documents the value of preoperative evaluation.
  
3. Lymphedema is often listed as a complication of breast cancer surgery. As the condition is a direct consequence of surgery, we would want our surgeons, oncologists and radiation oncologists to understand the condition and treatment: to assess for it and be able to assist in management. Patients with lymphedema often feel abandoned, as no physician will manage their care—please actively manage and support this known complication of breast cancer treatment. Studies support the lack of physician involvement in managing lymphedema: "A striking feature of these findings is the disparity in what patients expect from their physicians and how physicians view their roles as a resource for lymphedema education and counseling. **While women viewed their physicians as a primary source of information and counseling, physicians saw their role in this regard as minimal.**"
  - *Lymphedema: Knowledge, Treatment, Impact.* The Breast Journal, Vol 6, #6, 2000
  
4. Radiation oncologists need to be aware of the risks of lymphedema from radiation therapy. Many radiation oncologists continue to tell their patients that radiation of the level 1 axillary nodes does not cause lymphedema, and it's clear that it is a risk for both arm and breast edema—the risk of arm edema is increased by 3-7% and up to 70% of patients who have radiation develop sub clinical breast lymphedema.. Be specific with us about what part of the axilla will be in the radiation field. Discuss with us techniques that might be used to avoid irradiating healthy tissue unnecessarily (such as prone

positioning, IMRT). Please don't tell us that radiation does not cause breast, arm and possibly trunk edema. Several articles state that lymphedema is a known complication of radiation therapy. Radiation does increase the incidence of lymphedema, although it is unclear to what degree; please do not deny that reality.

- "Lymphedema of the Arm and Breast in Irradiated Breast Cancer Patients: Risks in an Era of Dramatically Changing Axillary Surgery", (The Breast Journal, Vol 10, #5, 2004, pp.405-411)
- "Lymphedema Secondary to Postmastectomy Radiation: Incidence and Risk Factors", (Annals of Surgical Oncology, 11(6)573-580,2004). "Breast Radiotherapy and Lymphedema," (Presented in Part at the American Cancer Society Workshop, New York, New York, February 20-22, 1998.)
- "Complications of Breast-cancer Radiotherapy." E. Senkus-Konefka, and J. Jassem

5. When you refer a patient for lymphedema therapy, please maintain contact with that patient through follow-up visits. Patients at risk for and affected by lymphedema will need periodic medical re-evaluation, and their prescriptions for lymphedema garments and equipment will need to be renewed annually. Your patients will appreciate being able to discuss the progress of their therapy with you. In addition, you may learn of strengths or shortcomings of the lymphedema clinic to which you are sending your patients.

6. We ask that you acknowledge the link between breast surgery and treatment and development of lymphedema. Many surgeons understate the risk of lymphedema, especially in patients having only one or two lymph nodes removed. There are no standardized definitions of lymphedema, and follow up is usually much shorter than 20 years, but at 6 months of follow up, 7% of patients with sentinel node biopsy developed significant clinical lymphedema in one study. Lymphedema increases in incidence with prolonged follow-up. For axillary node dissection the incidence was 49% after a 20-year follow up, with 1% of additional patients developing the condition for each additional year of follow up.

- "Sentinel Biopsy and Axillary Dissection: Added Morbidity of the Arm, Shoulder and Chest Wall after Mastectomy and Reconstruction", (The Cancer Journal, Vol. 14, #4, July/August 2008);
- "McLaughlin, S.A. et al.: Prevalence of lymphedema in women with breast cancer 5 years after sentinel lymph node biopsy or axillary dissection: Objective measurements." (Journal of Clinical Oncology, Vol. 26, No. 32 (November 10), 2008: pp. 5213-5219);
- "McLaughlin, S.A.: Prevalence of lymphedema in women with breast cancer 5 years after sentinel lymph node biopsy or axillary dissection: Patient perceptions and precautionary behaviors." (Journal of Clinical Oncology, Vol. 26, No. 32 (November 10), 2008: pp. 5220-5226.)

7. Consider providing over-the-counter compression sleeves and gauntlets to each patient who is undergoing breast cancer treatment. Those garments should be worn at the first sign of swelling, to reduce the severity of the problem. Every patient undergoing breast surgery is at risk of developing lymphedema at some point in her lifetime.
  
8. **Please don't tell a breast cancer patient that her risk of developing lymphedema is "zero" or "minimal" if she had a sentinel node biopsy rather than full axillary node dissection.**
  - "Lymphedema: Management in Era of Sentinel Node Biopsy", Oncology Times, 26 (4):12-17, 2/24/2004
  - "Sentinel Biopsy and Axillary Dissection: Added Morbidity of the Arm, Shoulder and Chest Wall after Mastectomy and Reconstruction", (The Cancer Journal, Vol. 14, #4, July/August 2008);
  - "Breast Lymphedema after Breast Conserving Treatment" (Acta Oncologica Vol.43, #6, pp.551-557, 2004);
  - "McLaughlin, S.A. et al.: Prevalence of lymphedema in women with breast cancer 5 years after sentinel lymph node biopsy or axillary dissection: Objective measurements." (Journal of Clinical Oncology, Vol. 26, No. 32 (November 10), 2008: pp. 5213-5219;)
  - "McLaughlin, S.A.: Prevalence of lymphedema in women with breast cancer 5 years after sentinel lymph node biopsy or axillary dissection: Patient perceptions and precautionary behaviors." (Journal of Clinical Oncology, Vol. 26, No. 32 (November 10), 2008: pp. 5220-5226.)
  
9. Patients should be informed of the specific location(s) from which lymph nodes were removed during sentinel node biopsy. The sentinel node(s) is/are not always found within the axilla. Because Lymphedema therapy includes massage to redirect lymph flow away from areas of compromised lymphatic drainage, it is important for the lymphedema therapist to know from where lymph nodes were removed.
  
10. Any patient who has surgery for breast cancer, including prophylactic mastectomy, should be given copies of the National Lymphedema Network position papers on lymphedema risk reduction, exercise and air travel, plus a link to the National Lymphedema Network website.
  
11. We recommend that "Lymphedema Risk Reduction" classes be made available for your breast surgery patients, just as "Look Good—Feel Better" classes are provided for patients undergoing chemotherapy. This might be something coordinated through a local or regional American Cancer Society office. In a Lymphedema Risk Reduction class, a qualified lymphedema therapist would give a presentation, discuss risk reduction, show everyone what a compression sleeve and glove look like, and perhaps demonstrate basic Manual Lymphatic Drainage massage of the arm. Handouts would be

provided, including a list of "red flags" patients should watch out for that might indicate the development of lymphedema.

12. All members of the medical profession should take lymphedema seriously and refer at-risk or affected patients for lymphedema assessment and therapy. No breast cancer patient should have her lymphedema progress to Stage 2 or Stage 3 because of lack of prompt medical referral and attention.
13. We ask that you and your clinic or hospital staff honor the wishes of a breast cancer patient who requests that no blood draws, injections, or blood pressure measurements be done on an arm at risk of lymphedema. Please instruct all of your nurses and medical assistants to respect that request, rather than argue with the patient or suggest that she is wrong or ill-informed. She is not "being difficult"—she is trying to prevent the development of a serious, expensive, and lifelong medical condition.
14. It would be helpful if you could devise an efficient way for us to obtain the necessary prescriptions for lymphedema garments or equipment from your office. The terms and coverage allowances of our insurance policies vary, but they often require new prescriptions each year. When we call the customer service representatives at our insurance companies, the clerks often cannot tell us whether, or how many, lymphedema garments our policies cover. They ask us for the insurance code numbers for those items. We might need help from your office staff when complying with those requests, and when trying to obtain approval for insurance coverage.
15. As a physician who treats women with breast cancer, you are in a position to advocate for more effective education on lymphedema and the lymphatic system in medical schools and continuing education classes. Although the lymphatic system may be covered as a component of the immune system, those lectures rarely consider biomechanics and fluid dynamics of lymph flow, the role of the lymphatic system in protein and electrolyte balance, or anatomic details of lymphatic drainage patterns. Because lymphedema can develop many months, or even many years, after breast surgery, it is important for all physicians and other health care professionals to be knowledgeable about the treatment and prevention of lymphedema.
16. Please do not make it difficult for us to obtain a prescription for an antibiotic to have on-hand in case of cellulitis. We are not using antibiotics as "recreational drugs." We may be far from a doctor, hospital or emergency room at the time we sustain an injury or develop an infection in the at-risk arm, and rapid antimicrobial treatment is essential. Multiple studies have documented that cellulitis is a risk factor for severe lymphedema. The position of the National Lymphedema Network is that we should be treated immediately if any signs of cellulitis develop: as there are access to care issues and lack of wide spread knowledge about lymphedema, a prescription

- of antibiotics to initiate immediate treatment of cellulitis should be the standard of care for all patients with lymphedema. In this era of overuse of antibiotics and resistance to prescribing antibiotics, we still need to have the ability to treat at the first sign of infection—a small scratch, if left untreated, could mean the development of serious systemic infection.
17. Please help us learn how to distinguish normal postoperative swelling from early lymphedema. We do not want to over-react. We do want to know what signs would signal a more serious condition that warrants an office visit. We want to know when we should seek help to keep the situation from becoming advanced or even irreversible lymphedema. Since many doctors are unfamiliar with this condition, please refer us to a lymphedema therapist for evaluation at the earliest suspicion of lymphedema rather than "wait and see."
  18. Some of the employees at your hospital or clinic who have contact with breast cancer patients may not be aware of lymphedema as a complication of breast surgery. We need you to educate your medical and office staff to be sensitive to our concerns about the swelling and pain of lymphedema.
  19. The pain from lymphedema can be very difficult for us to control using over-the-counter analgesics and even narcotic pain medication. If we complain of continuing pain that we are unable to control with the medications you have recommended, please be ready to refer us to a physician or clinic with expertise in pain management. A consultation with a pain management clinic can be extremely helpful in improving our quality of life.
  20. If you perform breast surgery in coordination with a plastic and/or reconstructive surgeon, we ask that you be sure the plastic surgeon knows about lymphedema. Worsening of lymphedema may occur following certain types of reconstructive surgery, so those surgical procedures might be contraindicated in some patients. For example, a woman who already has lymphedema in her arm or breast is at increased risk of developing truncal lymphedema following a TRAM procedure. Lymphedema can be triggered in an at-risk patient even when no lymph nodes are removed. We quote from the NLN article on *Lymphedema Awareness Vol. 10, no.3, 2002:*

"Some women opt to have the TRAM flap procedure which uses the rectus abdominus muscle (abdominal muscle). The muscle, fat and skin are pulled up to the breast area without cutting the original blood vessels. This procedure requires a large abdominal incision which is somewhat of a concern, especially in the patient with bilateral mastectomies and existing arm lymphedema, since there are very few options left in the body for re-routing the lymph fluid (and since the procedure weakens the abdominal wall)."

21. "Lymphedema" should be listed as a post-surgical risk on the informed consent documents we sign prior to breast surgery and radiation therapy.
22. Please be sure you and your medical staff members are aware of the current information regarding risks and prevention of lymphedema. It is not uncommon for patients to be told they "should not lift anything over five pounds," or, conversely, that they have no risk of lymphedema so no precautions are necessary. We recognize that medical professionals may disagree about the magnitude of the risk of lymphedema, especially with less extensive nodal surgery. We also acknowledge that patients may over-react when informed of their risks. However, because of the serious consequences for our quality of life with a diagnosis of lymphedema, and the lifelong risk, we prefer that you give each of us clear information about this condition and the steps we can take to reduce our risk, so that we can make informed decisions on our own behalf.

### **TO OUR DOCTORS, NURSES/PHYSICIAN ASSISTANTS/NURSE PRACTITIONERS/PHLEBOTOMISTS**

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23. Please don't argue with your patients when they ask you not to do any procedures (venipuncture, injections, blood pressure measurements) on their "bad" or at-risk arm. Exactly what triggers development of lymphedema, and which patients will develop it, are not known. We would rather be too cautious than sorry.

24. Realize that, just because the swelling is not visible to you, that does not mean your patient does not have lymphedema.
25. Be observant. Your patient may



be wearing a medical alert bracelet or other identification that warns about restrictions on the use of on one or both arms. She may be wearing a compression sleeve or bandage. Please take the time to read and note (chart) those items, and understand their significance. Your patient is especially dependent on you when she is under the influence of sedatives or anesthesia. Please pay attention to any alert bracelets and/or g-sleeves that we may be wearing to identify ourselves as either having lymphedema or being at risk for lymphedema.

See: NY Assembly Passes Maisel Measure To Raise Awareness of Lymphedema, NYS Assembly Bill A05892, and we quote:

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EXPLANATION--Matter in *ITALICS* is new; matter in brackets { } is old law to be omitted.

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"(c) Lymphedema AND LYMPHATIC DISEASE, an abnormal swelling of the extremities including the causes {and}, symptoms *AND NATURE of PRIMARY AND SECONDARY* lymphedema *AND LYMPHATIC DISEASE, PREVENTION, EARLY DIAGNOSIS, CURRENT AND NEW AND EMERGING OPTIONS FOR TREATMENT AND THERAPY, RESEARCH, MEDICAL INSURANCE, LONG-TERM CHRONIC CARE ISSUES, AND CONTACT AND VOLUNTARY ENROLLMENT INFORMATION FOR THE NATIONAL PATIENT REGISTRY TISSUE/CELL BANK FOR LYMPHATIC DISEASES*, the value of early detection, possible options for treatment including their benefits and risks, and other relevant information and the recommendation that hospitals treating breast cancer patients implement a lymphedema alert program by placing a bright pink wristband on the patient's affected arm." (Underlining emphasis supplied)

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26. If you work with breast cancer patients in a hospital or outpatient surgery setting, please check to see that a sign is posted above the bed, warning that the left (or right) arm (or both arms) should not be used for venipuncture,

- injections, or blood pressure measurements. If there is no sign, ask that one be placed there. If there is a sign, be sure the other medical staff see it and comply with what it says. And, please don't allow other staff members to argue with the patient or insist on using the at-risk arm just because the other arm is less convenient.
27. If you are a nurse-educator, be an advocate for your breast cancer patients and their nurses. Arrange for inclusion of lectures on lymphedema in nursing programs and continuing education courses. Ask that lymphedema prevention and management be included on licensure or certification examinations.
28. We know it is more difficult to take the measurement of blood pressure from our thighs or draw blood from, or place I.V.'s in, the veins of our feet. Sometimes that is our only recourse, if both our arms are at risk or are already affected by lymphedema. So, be sure you and your colleagues know how to take a blood pressure measurement on a patient's leg. Be sure you can draw blood from, and insert an I.V. catheter into, a leg or foot vein. If this is difficult for you, find someone who can assist you.