NATIONAL LYMPHEDEMA NETWORK

NLN
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NATIONAL LYMPHEDEMA NETWORK
Latham Square
1611 Telegraph Avenue, Suite 1111
Oakland, CA 94612-2138
Telephone 510-208-3200
Website www.lymphnet.org
E-mail nln@lymphnet.org

The NLN Mission Statement

The mission of the National Lymphedema Network is to create awareness of lymphedema through education and to promote and support the availability of quality medical treatment for all individuals at risk for or affected by lymphedema.

The NLN is dedicated to:

- *promoting research into the causes, prevention and treatment of lymphedema;*
- *securing adequate insurance coverage for medically necessary, safe and effective treatment;*
- *expanding the number and geographical distribution of lymphedema treatment facilities and certified therapists.*

To achieve these goals, the NLN disseminates information about lymphedema to healthcare professionals so they can appropriately counsel their patients on its avoidance, and prescribe safe, effective treatment for those affected by this condition. The NLN also provides this information to the general public.

Lymphedema Secondary To Treatment For Breast Cancer: A Multi-Disciplinary Approach

In 2005, under the leadership of the chief of breast radiation oncology, the Breast Center at Massachusetts General Hospital in Boston began a team approach to address breast cancer-related lymphedema. In the following articles and case studies, we plan to share our experience, outline our work to date, and illustrate what can be accomplished with a dedicated multi-disciplinary team effort. The success of working as a team has motivated us to pass this message along to others. We hope to encourage our colleagues in the field of lymphedema to consider developing a lymphedema team. We also hope to demonstrate how this framework can be applied and/or adapted to other practice settings.

Successful Management Requires a Team Approach: The Why, Who And How Of A Team

By Jean O'Toole PT, MPH, CLT-LANA

Why did we decide to create a team approach?

The many quality of life challenges that patients face following treatment for breast cancer are well documented.[1-5] Lymphedema is clearly one of the major challenges for patients in whom it occurs. It can also be a significant source of distress for patients who fear its development.[6] Four years ago, a few of us involved in the care of these patients questioned if, as a Breast Center, we were doing enough to confront this often devastating side effect of breast cancer treatment. We recognized that the needs of patients with breast cancer-related lymphedema were varied and complex, requiring the skills of different disciplines. As in many other models in medicine, we determined that this problem would likely be more effectively managed if we took a structured multidisciplinary approach to breast cancer related lymphedema.[7,8] Thus, our multidisciplinary team was created with only three initial members. We agreed on the overarching goal of addressing breast cancer related lymphedema proactively, aggressively and comprehensively, and to stay focused around patient centered goals. Since its inception, our team has added members, learned and reflected on our efforts, and has continued to evolve. However, our mission has remained the same: to identify lymphedema as early as possible, empower patients to manage lymphedema with as little burden as possible while keeping their goals central to decision making, and to contribute to the scientific literature regarding evaluation and management.

Who is on the team and what are the roles?

Appreciating that a variety of providers would bring a broader perspective to the patient experience, we have made a

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The goal of this publication is to provide information specific to the needs of lymphedema patients and health care providers.

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conscious effort to be inclusive. We worked to develop a network of colleagues who were passionate about organizing their efforts around this problem. Presently, the team members include the patient and their support system, colleagues from surgical, medical and radiation oncology, and certified lymphedema therapists. We consider the Cancer Center nutritionists, social workers, our Cancer Resource room staff, and representatives from the Wellness community as essential to the team effort. The Durable Medical Equipment (DME) provider is also an important member of the team. The roles of team members are varied and the level of involvement of team members depends on the needs of the patient. However, discussing lymphedema openly and willingly with all patients is an expectation for everyone at the Breast Center. Attention to breast cancer related lymphedema has grown in our setting. Throughout our Breast Center, it is universally recognized as a serious and real side effect that warrants ongoing monitoring and attention.

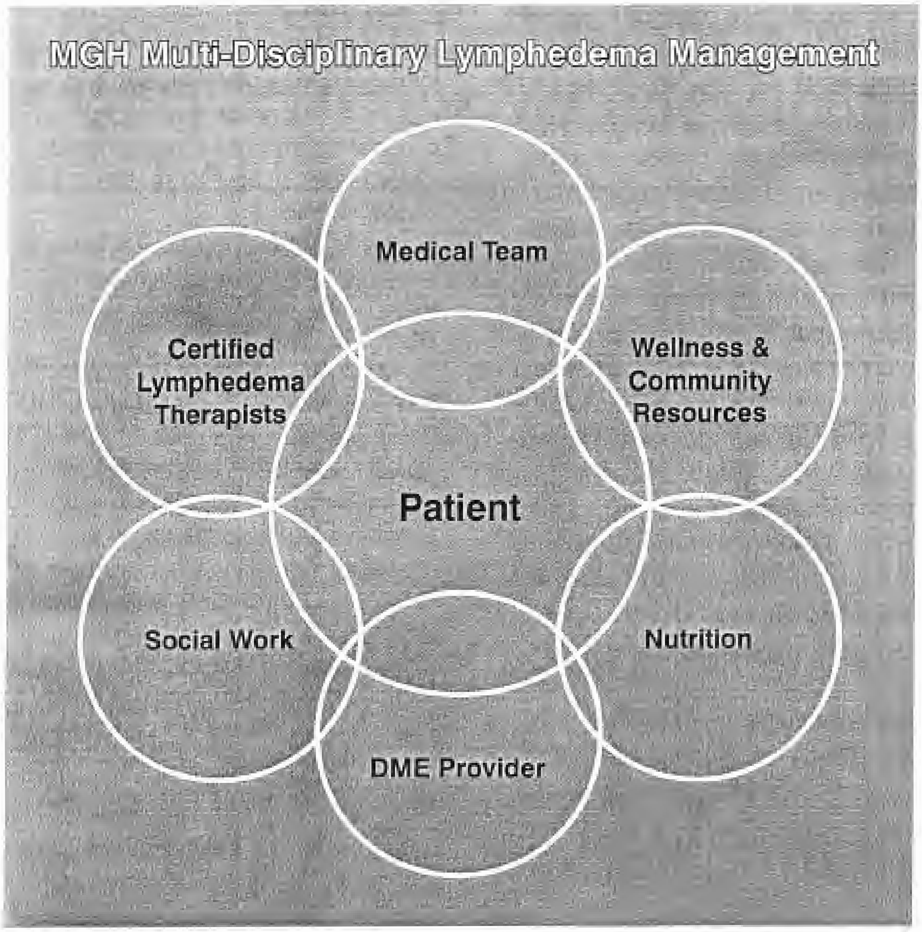
Our lymphedema team coordinator is from the department of radiation oncology and has the primary responsibility of measuring patients on the perometer, organizing and interpreting the data. Patients are measured at the time of diagnosis, post- operatively, at the completion of chemotherapy, at the end of radiation, and then every four to six months for all of their years of follow up. This has provided us the opportunity to understand the natural history of lymphedema and enabled us to embark on projects of scientific inquiry. The presence of the perometer in the Breast Center has made regular assessment of arm volume possible and efficient. It affords the patients a readily accessible tool to help address their concerns regarding edema development. Furthermore, it also accurately quantifies the efficacy of our interventions.

The medical, surgical and radiation oncology providers of care are essential. We rely on them to rule out occult disease or a vascular event that might be responsible for new lymphedema. These physicians and nurses are in a pivotal position to refer patients for care, ensure that perometer readings are performed regularly, and communicate patients' medical considerations to the rest of the team.

The social workers assigned to the Breast Center play an essential role, providing emotional support, assisting with transportation, pursuing opportunities for financial assistance and providing a link to community resources. It is these social workers who assist patients with completing forms for financial need. They are available for ongoing psycho-social support as patients cope with their lymphedema. In situations where additional mental health services are warranted, our physicians in the Psychiatric Oncology Department become involved. Our Cancer Center nutritionists also are involved as they are able and available to counsel patients on dietary considerations. Given the association of high body mass index with lymphedema their efforts in helping patients control their weight are invaluable.[9,10]

There are three certified lymphedema therapists on our main campus in Boston, and two in hospital affiliated healthcare centers located outside of the city of Boston. These five clinicians are also experienced orthopedic therapists who are capable of managing not only patients' lymphedema, but their musculoskeletal problems as well. We have intentionally supported these staff members, enabling them to go through the lymphedema training and certification as edema therapists and placed them in strategic locations to make it easier for patients to receive care closer to their homes. In addition, with intent to increase the number of trained providers in our area, MGH Physical Therapy Service hosted the Lymphedema Certification Course on three occasions. We also have compiled a list of certified lymphedema therapists by geographical area, locally and throughout New England, which enables us to recommend qualified providers in areas more accessible for our patients who do not live near our hospital.

We rely on a licensed DME provider to measure for custom garments and bill insurances. Specifically, our clinic has an experienced fitter who comes to the hospital on



a weekly basis and provides this much needed service to our patients.

The Cancer Resource Room at our hospital contains booklets and books on all cancer related topics, has computers available for patient use, and a classroom. Free classes and workshops on lymphedema, exercise, nutrition and fatigue are offered daily, and members of our team participate regularly, depending on the topic.

How does the team process work?

Open and regular communication strategies enable the team to coordinate their efforts. The team meets regularly to review goals and progress and adjust plans accordingly. In between meeting times, email serves to share ideas, pose questions, obtain feedback on abstracts, manuscripts, and report on any educational meetings, talks or opportunities. The electronic medical record (LMR) serves as a central repository for patients' visit data, phone calls, pathology reports, operative notes etc. Perometer readings are also documented in LMR, so all providers can easily access that information. If patients present with an urgent problem, a needed colleague can be contacted by page to address the request for help. A recent case demonstrates this well: A patient was coming in for regular Complete Decongestive Therapy (CDT) and her edema was responding well to treatment. She came to her regular appointment on a Monday, reporting a 24-hour period of increased swelling and pain. Indeed, on examination, her arm was markedly more edematous and discolored. The lymphedema therapist paged the nurse practitioner for the medical oncologist who was caring for the patient. The patient was measured on the perometer and a doubling of her volume was confirmed. She was referred for imaging within a few hours, and revealed a deep vein thrombosis in the subclavian vein. Anti coagulation was initiated immediately.

The challenge of obtaining funds for patients whose insurance does not cover garments has been facilitated by a grant funded by a local philanthropic group. The distribution of funding is managed by our social workers who are just an email away when there is a patient in need. We have also obtained funding for this purpose through a grant from our Friends of the Cancer Center.

Some examples of our team efforts are:

1. A lymphedema teaching sheet was developed to provide patients with reliable information regarding risk factors and answers to frequently asked questions specifically for breast cancer related lymphedema.[9,11,12] It was created utilizing input from the surgical and nursing staff in the Breast Center as well as the lymphedema therapists. The draft was reviewed by the team and feedback from all of the Breast Center providers was incorporated. It is now available to patients in hard copy and also on our Cancer Center website.

2. The HOPES Program (part of our patient support services), the Breast Center and an affiliated Health Club are sponsoring an eight-week Pilates Following Breast Cancer class. This is made available free of charge to our patients through a special fund from the Breast Center, which was made possible through a grant request submitted by one of the lymphedema therapists. The Pilates instructor, lymphedema therapist, social worker and a nurse practitioner from the Plastic Surgery department met and discussed any restrictions required for individuals enrolled in the class. HOPES obtained consent from the patient's surgeon and/or medical oncologist. Perometer readings will be performed pre and post class.

3. We also reach out to members of The Wellness Community who are providing exercise classes for patients, so that we can be aware of the content and feel confident about referring patients to other venues. The data from

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the exercise trials that are evaluating the impact of exercise on lymphedema is rich and our team works to stay abreast of new developments and resources that are available for patient near their home or work.[13-17]

4. The social workers run several support groups for breast cancer patients and routinely include the lymphedema therapists, who come and talk with patients about lymphedema, exercise and caring for their bodies. Patient feedback has been very positive as patients with lymphedema as well as those without this condition voice appreciation that the topic is so out in the open here. They tell us that they feel comfortable and safe discussing lymphedema and asking any questions they may have. These are just some examples of the many types of interactions the team has that focus on actively working together in the effort of approaching breast cancer related lymphedema with educational and exercise opportunities. Other team projects and team efforts around patient care will be demonstrated in the following article and case studies.

Summary

A team approach is possible when even a few committed providers who are passionate about addressing lymphedema begin to work together to identify needs and develop action plans. It has been our experience that a willingness to openly discuss lymphedema very early on in the patient experience and regular respectful communication are key behaviors for success. It seems that this openness establishes a culture of recognition in the practice environment, that lymphedema is a serious problem and worthy of proactive management. Strong communication strategies allow all parties involved to remain abreast of developments regarding patient needs and also provide opportunities for growth. It has been our experience that a dynamic team evolves and expands over time, and we continue to appreciate the need for other disciplines to join in the effort.

We believe that this team concept is applicable to other causes of lymphedema, and the composition of the team will vary depending on patient populations and resources. For example, in a team dedicated to vascular edema, nutritionists and exercise physiologists may play a major role. A team working together on edema related to pelvic surgery may need to include practitioners skilled in managing pelvic floor dysfunction. Regardless of the practice setting, we encourage our colleagues around the world to partner with others in their locale to take this problem on, not just as sole practitioners, but in a collegial approach with the needs of the patient driving their efforts. It can begin as a small group,with modest goals, but we will never know what can be accomplished, unless we begin. ❑

References

1. Hayes SC, Janda M, Cornish B, et al: Lymphedema after breast cancer: incidence, risk factors, and effect on upper body function. J Clin Oncol 26:3536-42, 2008
2. Paskett ED: Breast Cancer-Related Lymphedema: Attention to a Significant Problem Resulting From Cancer Diagnosis. J Clin Oncol, 2008
3. Ridner SH: Quality of life and a symptom cluster associated with breast cancer treatment-related lymphedema. Support Care Cancer 13:904-11, 2005
4. Oliveri JM, Day JM, Alfano CM, et al: Arm/hand swelling and perceived functioning among breast cancer survivors 12 years post-diagnosis: CALGB 79804. J Cancer Surviv, 2008
5. Beaulac SM, McNair LA, Scott TE, et al: Lymphedema and quality of life in survivors of early-stage breast cancer. Arch Surg 137:1253-7, 2002
6. Lee TS, Kilbreath SL, Sullivan G, et al: The development of an arm activity survey for breast cancer survivors using the Protection Motivation Theory. BMC Cancer 7:75, 2007
7. Dos J, Gorska-Dos M, Szuba A: The integrated and interdisciplinary treatment of chronic lymphedema. Rocz Akad Med Bialymst 50 Suppl 1:141-4, 2005
8. Salas E, Wilson KA, Murphy CE, et al: Communicating, coordinating, and cooperating when lives depend on it: tips for teamwork. Jt Comm J Qual Patient Saf 34:333-41, 2008
9. Vignes S, Arrault M, Dupuy A: Factors associated with increased breast cancer-related lymphedema volume. Acta Oncol 46:1138-42, 2007
10. McLaughlin SA, Wright MJ, Morris KT, et al: Prevalence of Lymphedema in Women With Breast Cancer 5 Years After Sentinel Lymph Node Biopsy or Axillary Dissection: Patient Perceptions and Precautionary Behaviors. J Clin Oncol, 2008
11. Nielsen I, Gordon S, Selby A: Breast cancer-related lymphoedema risk reduction advice: A challenge for health professionals. Cancer Treat Rev 34:621-8, 2008
12. Tsai RJ, Dennis LK, Lynch CF, et al: The Risk of Developing Arm Lymphedema Among Breast Cancer Survivors: A Meta-Analysis of Treatment Factors. Ann Surg Oncol, 2009
13. Cheema B, Gaul CA, Lane K, et al: Progressive resistance training in breast cancer: a systematic review of clinical trials. Breast Cancer Res Treat 109:9-26, 2008
14. Cheema BS, Gaul CA: Full-body exercise training improves fitness and quality of life in survivors of breast cancer. J Strength Cond Res 20:14-21, 2006
15. Ahmed RL, Thomas W, Yee D, et al: Randomized controlled trial of weight training and lymphedema in breast cancer survivors. J Clin Oncol 24:2765-72, 2006
16. Knobf MT, Insogna K, DiPietro L, et al: An aerobic weight-loaded pilot exercise intervention for breast cancer survivors: bone remodeling and body composition outcomes. Biol Res Nurs 10:34-43, 2008
17. Hayes SC, Reul-Hirche H, Turner J: Exercise and secondary lymphedema: safety, potential benefits and research issues. Med Sci Sports Exerc 41:483-9, 2009

Jean O'Toole works as a Clinical Specialist in the Physical Therapy Department of Massachusetts General Hospital. She received her B.S. in Physical Therapy from Northeastern University in 1970, a Masters in Public Health from Boston University in 1991, Klose-Norton training for lymphedema in 2002, and was LANA certified in 2003. Email jotoole2@partners.org