

# HANYS

HEALTHCARE ASSOCIATION OF NEW YORK STATE

THOMPSON HEALTH

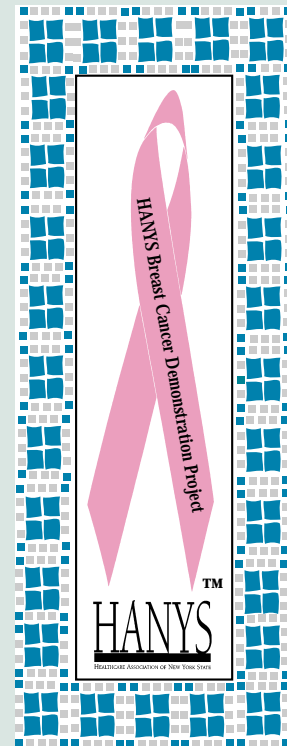
## Preventing and Treating Lymphedema

**T**hompson Health, an integrated health care system in Canandaigua, used its participation in the HANYS Breast Cancer Demonstration Project™ (HANYS BCDP™) to develop a lymphedema prevention and treatment program that incorporates the latest techniques for reducing swelling associated with lymphedema and for improving patient functioning. This *Best Practice Strategy Guide* presents a model that hospitals can employ for successfully treating patients diagnosed with this complication.

### About Lymphedema

Lymphedema is a progressive swelling of the tissue close to the skin's surface. Lymphedema most often develops after surgical procedures such as axillary lymph node dissection (ALND) or radiation treatments to the axilla. Estimates of lymphedema's prevalence among breast cancer patients ranges from 2% to 24% among women undergoing ALND. Although lymphedema is often preventable and treatable, the diagnosis of lymphedema can be a difficult one for patients who believe they have put intensive medical treatment behind them.

Lymphedema occurs when the flow of protein-rich lymphatic fluid is impaired and accumulates because of damage to the lymph vessels and lymph nodes located along the vessels. Radiation therapy and procedures such as ALND that require the removal of lymph nodes from the axilla can damage lymphatic pathways. This, in turn, can block the flow of the lymphatic fluid, resulting in a pooling of fluid throughout the affected arm. If left untreated, the condition will worsen and the



## Best Practices Strategy Guide

© 2002 Healthcare Association of New York State. All rights reserved.

## NOTES ON LYMPHEDEMA

- ◆ *Lymphedema is a swelling that occurs when flow of lymph is interrupted by damage to lymphatic pathways.*
- ◆ *Among breast cancer patients, damage to lymphatic pathways most often occurs because of axillary lymph node dissection and/or radiation therapy to the armpit.*
- ◆ *Besides discomfort and swelling in the arm, lack of mobility, and limitations on activity, women experience significant psychological and emotional repercussions from lymphedema.*
- ◆ *There is no cure for lymphedema. However, advances have been made in its prevention and management.*
- ◆ *Education of patients and professionals is of foremost importance in preventing lymphedema.*
- ◆ *Research indicates that health care providers underestimate the impact of lymphedema; therefore, patients are not provided the necessary information and referrals for prevention and early detection.*
- ◆ *Additional research is needed on effective treatment methods.*
- ◆ *There are only a handful of certified lymphedema therapists in New York State. Currently, there is limited access to continuing education in decongestive therapy and manual lymph drainage in New York State.*

swelling can interfere with wound healing, which may provide a medium for infection-causing bacteria.

## Identifying the Need for a Lymphedema Program

Lymphedema often develops months or even years after surgery and some experts suggest that the risk increases with time and long-term opportunities for lymphatic damage. It is a chronic condition that causes swelling, tightness, and heaviness in the arm. Patients also experience recurrent skin infections. Patients' mobility may be impaired and their activities limited. The condition is also a physical reminder of breast cancer and, therefore, often causes psychological and emotional difficulties for women.

## Developing a Solution: What Thompson Health is Doing

While lymphedema cannot be cured, its damaging effects can be minimized through intensive therapy and patient education.

Linda Janczak, President and Chief Executive Officer of Thompson Health in Canandaigua, noted that the system joined HANYS BCDP™ in November 1999 and responded to patients' needs with a specialized, mostly outpatient, lymphedema prevention and treatment program.

Joni Tiller, Chief Executive Officer of F.F. Thompson Hospital, describes the new program as integral to comprehensive breast cancer education and services to women throughout New York's Finger Lakes region. Lorie Henley, R.N., B.S.N., M.S. Ed., Assistant Director of Thompson Health's Wellness Center, noted that Thompson Health's lymphedema program offers patients a variety of services. She said health care providers can teach and empower women to take charge of their health care. "You can check your breasts, you can go for a mammogram, you can protect against trauma and bruising to the affected arm, and you can go for treatment for lymphedema care," she said. "The lymphedema program improves the quality of life for women with breast cancer."

Thompson Health staff considered patients' needs when deciding to start a lymphedema treatment program. Oncologists, nurses, and physical and occupational therapists heard patients say they wanted to know how to prevent the onset of lymphedema and how to take care of themselves after it appeared. In the past, some patients traveled out of state for specific lymphedema therapy.

Mary Kay Musnicki, Coordinator of The Sands Cancer Center at Thompson Health, recalls a telephone call from a woman who had emotionally weathered breast cancer surgery several years previously,

but now was distraught over a new lymphedema diagnosis. “This was powerful to me that she had been doing well until lymphedema set in,” Ms. Musnicki said. “It’s interesting to see that you think you make it through the most difficult thing (breast cancer), and then you get slammed with this.”

Tony Ringo, A.T.C., Director of Rehabilitation Services, and Marilyn Herbert-Ashton, R.N., M.S.N., former Director of the Wellness Center, laid the groundwork for the development of the lymphedema treatment program at Thompson Health. Education of staff was the first priority.

Occupational Therapist Courtney Middleton attended a two-week intensive program at the Academy of Lymphatic Studies in Sebastian, Florida, with instructor Joachin Zuther, returning with certification in complete decongestive therapy and manual lymph drainage, the two main components of treatment. A second occupational therapist, Michelle DeRue, later received certification to handle the growing caseload. These individuals are now listed by the National Lymphedema Network and are among only a handful of certified therapists in New York State.

Most patients start with five weeks of daily, hour-long therapy sessions to reduce the swelling and learn self-care. Once the condition has stabilized, they have enough information to manage the condition at home with occasional follow-up visits for re-evaluations.

Traditional lymphedema treatment included anti-inflammatory medications, edema massage, and compression pumps that moved the excessive fluid in the arm into the armpit. However, these treatments were not only found to be ineffective, but could actually worsen the condition.

Thompson Health incorporates the most up-to-date, recommended treatments in its intensive five-week program:

- Wearing short-stretch bandages on the affected arm for 23 hours a day, between therapy sessions, to prevent the re-accumulation of fluid—the bandages exert minimal pressure when a patient is at rest and exert greater pressure when a patient is engaged in physical activity.
- Using “manual lymphatic drainage,” which is a gentle touch technique that directs fluid from the lymph nodes on the affected side of the body into normal functioning lymph vessels and nodes.
- Conducting upper arm exercises that improve muscular contractions and help provide a counter pressure to keep the lymph fluid moving and exercises that improve joint mobility and reduce muscle atrophy.
- Emphasizing skin and nail care to reduce the risk of infection, a major concern for patients with lymphedema.

#### THOMPSON HEALTH’S INITIATIVES:

- ◆ *Certification of on-site occupational therapists in lymphedema treatment methods.*
- ◆ *Five weeks of daily, hour-long therapy for enrollees with emphasis on patient education and information, encouraging self-sufficiency in treatment.*
- ◆ *Reliance on up-to-date, empirically proven treatment methods.*
- ◆ *Working with patients in justifying need for reimbursement from insurance companies that do not already provide reimbursement.*
- ◆ *Strongly advocating for establishment of a national Medicare policy for lymphedema treatment.*

### SELECTED OUTCOMES

- ◆ *Since the program began, 50 patients participated, 35 of whom were breast cancer survivors.*
- ◆ *Twenty-five (83%) of the 30 breast cancer survivors successfully completed treatment; at this writing, five are currently receiving treatment.*
- ◆ *Only five (17%) of the 30 patients returned for a “tune up” after exacerbation of their condition (increase in edema) due to injury, surgery, infection, and/or non-compliance with recommended management techniques.*

The therapist begins teaching patients these steps almost immediately to prepare them for long-term self-care. At the first session, the therapist measures both arms to compare the circumference of the swollen side to that of the non-affected side. The patient's affected arm is measured each Monday and Friday during the intensive phase of the program to determine the patient's progress and response to therapy. Photos of the patient are taken at the initial evaluation and then again at discharge and are included in the medical records. By the end of the first week, patients learn to apply the bandages themselves so that they can continue the 23-hour-day regimen throughout the weekend. They later learn how to do manual lymphatic drainage.

At the end of the intensive phase of the program, the therapist fits patients for a compression garment, a tight-fitting piece of elastic clothing that covers all or part of the arm and that puts pressure on the swollen arm and stops the collection of lymphatic fluid in any one area. Patients wear compression sleeves throughout the day and continue to wear the bandages at night.

The therapist asks patients to identify the lymphedema-caused limitations that make them most unhappy. Ms. Middleton recalled several patients who reported difficulty finding clothing to fit. Others reported an increase in swelling when they are engaged in activities such as childcare, gardening, and house cleaning. Patients receive instruction regarding methods for easing swelling and preventing infection. These include maintaining an ideal body weight, avoiding heavy lifting with the affected arm, keeping the arm protected from extreme temperature changes and from the sun, and avoiding any trauma to the arm. Patients also learn energy conservation techniques and safety precautions, such as wearing gloves during gardening to prevent cuts that could cause infections. Thompson Health provides information to patients about the use of a special medical identification bracelet that alerts health care workers not to draw blood, give an injection, or apply a pressure cuff to the affected arm.

Ms. Middleton also educates patients about treatment outcomes. Although patients cannot always expect 100% improvement, the most significant results, as defined by reductions in swelling, are typically achieved during the first week of treatment.

Once patients shift from the intensive therapy phase to at-home self-care, they return to the hospital outpatient clinic every three to six months for follow-up visits. During these visits, the therapist measures the size of the affected arm to determine whether the swelling has remained stable. The therapist also measures the patient for a new compression garment, if needed, and shares any new medical developments in managing lymphedema with the patient.

Thompson Health noted that most insurance companies have covered some portion of the treatment costs for their patients. In cases where insurance companies do not routinely cover the cost of supplies (band-

ages and garments, for instance), the occupational therapists work with patients to help them provide the necessary information to document the need for reimbursement.

The National Lymphedema Network (NLN) reports wide discrepancies across the nation in insurance coverage for treatment. Some carriers reject lymphedema as an acceptable diagnosis for therapy even though there is a specific code for manual lymphatic drainage, and Medicare reimbursement policies vary among the states. New York Medicare policies include manual lymphatic drainage in the treatment of post-mastectomy lymphedema syndrome. Some health plans establish unrealistically low expectations as to the number of treatment sessions required to prepare seniors for a self-care program following clinical treatment, the NLN reports. NLN is pressing for a national Medicare policy for lymphedema treatment.

## Thompson Health Outcomes to Date

From December 1999 through June 2002, Thompson Health therapists worked with 50 patients. Thirty-five were breast cancer survivors; the others had survived other cancers or traumas or had congenital conditions in which lymphedema may have affected parts of the body other than their arms. Patients ranged from eight months old to more than 80 years old.

The patients averaged 15 visits to complete the treatment regimen. This average is low because some patients sought only single consultations on how to prevent lymphedema, while others required more visits to stabilize their condition.

Successful treatment outcomes are achieved if infections are prevented, patients feel better emotionally about themselves and their physical appearance, and patients are able to resume favorite activities that were previously curtailed by lymphedema. The greatest success is the patient's ability to independently manage the condition.

## Keys to Success

Staff at Thompson Health identified several factors that contributed to the early success of this program:

- 1. Ensuring professional staff receive specialized training and creating an interdisciplinary approach to care through close interaction among staff throughout Thompson Health's network of services.**

Thompson Health's lymphedema program relies on referrals from throughout the system, especially from the Cancer Center and Wellness Center. Therefore, the therapists offer in-service training to Cancer Center staff on what the program can offer patients so they can appropriately refer patients. The therapists attend cancer support groups to educate patients about lymphedema and its pre-

vention and treatment and work with other staff to educate the public through radio presentations and newspaper articles.

Lorie Henley, Assistant Director of the Wellness Center said, “This collaboration has provided an information base which has opened up communication lines and provided available services to patients.”

## **2. Building flexibility into the program to meet patients’ needs.**

In response to reports about the difficulty of attending daily sessions each week, the therapists customized the treatment regimen to better fit patients’ schedules. Some patients now come to the hospital three times a week or whenever they are able. Not every patient can come five days a week.

The therapists supplement the in-person sessions with videos that demonstrate the step-by-step process of bandaging and manual lymphatic drainage and provide printed handouts that clearly describe prevention tips.

## **3. Providing psychological and social support.**

The therapists help patients deal with body image, physical limitations, sexual attractiveness, and concerns that often emerge with swelling and wearing of bandages and a compression garment.

“Our greatest service to the patients is to listen to them, refer them to support groups, and share educational materials with them,” Ms. Middleton said. “To our patients it’s significant. They’re getting information from us they haven’t heard before.”

## **4. Adjust staffing to accommodate the number of patients seeking treatment and to maintain consistent treatment.**

Initially, Ms. Middleton worked part time with lymphedema patients, treating four patients a day. As the waiting list for participation grew, the hospital, with the help of a HANYS BCDP™ grant, invested in certification for a second therapist, who now works full time in the lymphedema program. This has eliminated the waiting list and allows for continued treatment if one therapist is on vacation or out ill.

## **5. Creating a private treatment area for lymphedema patients.**

Maintaining an atmosphere that promotes patient privacy is important. Ms. Middleton and Mr. Ringo turned a former conference room into a two-compartment treatment area separated from the rest of the open-space occupational therapy department at FE Thompson Hospital. A privacy curtain separates the two treatment spaces, each with a bed and a chair.

Ms. Middleton also designed a mobile lymphedema cart that includes a slip-out board for measuring an arm while a patient is sitting down and an instrument for measuring a leg. The cart, which can be wheeled between the two treatment spaces and to other rooms, also features storage drawers and shelves.

Lymphedema education is ongoing. Posters illustrating the lymphatic system hang on the walls of the treatment area and the staff plans to purchase a television and video unit to allow patients to watch educational videos during treatment.

## Future Courses of Action for Thompson Health

Thompson Health is looking ahead to further develop the program to address emerging patient needs.

The certified occupational therapists are beginning to extend their expertise to include a greater focus on prevention through consultations with women living with breast cancer before they see any symptoms of lymphedema. Staff advise patients about many of the same measures prescribed for self-treatment after diagnosis, such as wearing a compression garment during moderate to heavy activity. The therapists also take baseline measurements of patients' extremities to have comparison data in the event that these patients return later with early symptoms of lymphedema.

Thompson Health expects to expand its lymphedema services to inpatients through a new mastectomy exercise program, which includes lymphedema education for breast cancer patients immediately after surgery so that they can work to prevent the onset of the condition and look for its early signs. This new initiative, which originated with one of the hospital's "Do-it Groups," has brought together nurses, physical therapists, and occupational therapists. The group is putting together informational packets to give to patients before they are released from the hospital. The packets include lymphedema prevention tools including rubbing alcohol, a tape measure to pick up any signs of swelling, and bandages to immediately treat any cuts to the extremities.

Other plans include hosting a lymphedema support group, starting an aquatic exercise program for patients with lymphedema, and training staff internally so Thompson Health can provide additional lymphedema treatment hours.

As a longer-term goal, Thompson staff proposed advocating for additional regional access to education for health care providers in complete decongestive therapy and manual lymph drainage. Because of its high incidence and prevalence of breast cancer, New York State is an excellent location for this greatly needed treatment. Thompson Health hopes that by eliminating the inconvenience and expense of traveling out of state, more professionals will become qualified to treat the condition.

Thompson Health's participation in the HANYS BCDP™ helped the health system develop a state-of-the-art lymphedema program. The program builds from Thompson Health's commitment to excellence, action, respect, and serving the community.

### NEXT STEPS . . .

- ◆ *Expand focus on prevention of lymphedema.*
- ◆ *Expand lymphedema services to inpatients through a new inpatient pre-surgical mastectomy exercise program and providing lymphedema education.*
- ◆ *Train staff so Thompson Health can provide additional lymphedema treatment hours.*
- ◆ *Host a lymphedema support group and start an aquatic water exercise program for patients with lymphedema.*
- ◆ *Obtain national board certification as lymphedema therapists.*

**ONLINE LYMPHEDEMA RESOURCES**

**National Lymphedema Network (NLN)**  
(800) 541-3259 or (510) 208-3200  
www.lymphnet.org

NLN is an internationally recognized, non-profit organization dedicated to providing information about the prevention, management, and treatment of lymphedema. NLN offers educational information to lymphedema patients, health care professionals, and the public. A variety of resources are highlighted on its Web site, including treatment centers, support groups, suppliers, and educational materials.

**National Cancer Institute (NCI) Cancer Information Service**  
(800) 422-6237  
www.nci.nih.gov

NCI conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients. Lymphedema information may be accessed at this Web site by performing a search using the key term "lymphedema." NCI makes educational pamphlets and materials available free of charge to patients and health care professionals.

**American Cancer Society (ACS)**  
(800) 227-2345  
www.cancer.org

ACS is the nationwide community-based voluntary health organization dedicated to eliminating cancer as a major health problem. Through research, education, advocacy, and service, ACS prevents cancer, saves lives, and diminishes suffering from cancer. Lymphedema information may be accessed at this Web site by performing a search using the key term "lymphedema." ACS offers a patient education pamphlet titled, *What Every Woman Facing Breast Cancer Should Know About Lymphedema: Hand and Arm Care Following Surgery or Radiation Therapy for Breast Cancer*, along with other educational brochures, all available free of charge.

**Cancer Supportive Care**  
(510) 649-8177  
www.cancersupportivecare.com

The Cancer Supportive Care Web site features learning modules on cancer topics, including lymphedema.

**Thompson Comprehensive Health Care****THOMPSON HEALTH**

*Thompson Health (www.ThompsonHealth.com) is an integrated health care delivery system serving Ontario County and the surrounding Finger Lakes area. Thompson Health is the parent corporation that oversees the operation of seven affiliated health care organizations:*

- ◆ *F.F. Thompson Health System with 113 acute care beds,*
- ◆ *F. F. Thompson Continuing Care Center with 188 beds and two short-term stay beds, specializing in adult day services, Alzheimer's disease/dementia care, long-term care, and post-acute services.*
- ◆ *Finger Lakes Community Care Network, Inc.,*
- ◆ *FFTH Properties, Inc.,*
- ◆ *F.F. Thompson Foundation,*
- ◆ *Ontario County Advanced Life Support, and*
- ◆ *FFT Senior Communities, Inc.*

*Thompson Health also includes:*

**SANDS CANCER CENTER**

*The Sands Cancer Center provides a comprehensive, holistic approach to cancer care and treatment, including chemotherapy, radiation, clinical stud-*

*ies, integrated complementary medicine, a style shop, library, and support groups. This collaborative partnership created by Interlakes Oncology and Hematology, Strong Partners Health System, and Thompson Health combines the necessary expertise with seamless coordination of care, all in one convenient setting.*

**THOMPSON HEALTH WELLNESS CENTER**

*The Thompson Health Wellness Center is available to everyone who requires medical attention or wishes to enrich his or her mental and physical well-being. Support groups, a health and wellness resource library, wellness classes, programs and seminars, and an Integrated Complementary Medicine Center, together with friendly, professional health care staff, provide the community with the services needed for a holistic approach to wellness.*

**FINGER LAKES COMMUNITY CARE NETWORK-INDEPENDENT PHYSICIANS ASSOCIATION**

*In partnership with its physicians, Thompson Health co-owns Finger Lakes Community Care Network-Independent Physicians Association.*

*With a respected medical staff of more than 300, 1,300 staff members, and a community volunteer group with over 400 members, Thompson Health provides quality health care to more than 120,000 residents and their families in the Greater Finger Lakes Region. The health system's "CARES" values emphasize Commitment, Action, Respect, Excellence, and Service and guide Thompson Health associates and medical staff, Guild members, and volunteers at every point.*

HEALTHCARE ASSOCIATION OF NEW YORK STATE  
One Empire Drive, Rensselaer, NY ◆ 518.431.7600