

Social worker “champions” can expand their support programs and improve the patient experience.

GROWING GROWING GROWING GROWING

Your Cancer Support Services

BY AMANDA PATTON

North Shore University Hospital's Comprehensive Cancer Care Center

It is not uncommon for cancer support services to start small. In the case of this cancer center, which is part of the North Shore Long Island Jewish Health System, oncology support services began nearly 12 years ago with two American Cancer Society programs—*Look Good...Feel Better* and *Us TOO* (a prostate cancer support program). Flash forward to 2005. Today two full-time social workers staff a large and varied program of complementary services that are available to cancer patients, their families, and cancer center staff.

Rosemarie Ampela, LCSW, OSW-C, director of Oncology Support Services, attributes this dramatic growth to the ongoing sanction of department management to create wellness programs on site as well as the responsive participation of other staff (i.e., physicians, nurses, child-life specialist, oncology nutritionist) to co-lead, usually on a volunteer basis, in support groups of their choice. Ampela notes that patients often comment on how secure they feel to see their team “go the extra mile” for such comprehensive care.

What's even more amazing is that North Shore University Hospital's Comprehensive Cancer Care Center has been able to expand its Oncology Support Services *despite* growing cost-containment efforts from the government and private payers. Finding ways to help pay for these services has been a challenge, but well worth the effort. Not only are these services appreciated deeply by their cancer

patients, Oncology Support Services is one way for North Shore University Hospital to differentiate its cancer center from the competition.

In the past 12 years, North Shore University Hospital's support services program has grown to include a range of complementary services designed to assist patients from their cancer diagnosis through treatment and beyond. In a nutshell, here's how the program works.

Initially, an oncology social worker makes every attempt to meet with each new cancer patient at the hospital. Patients may be referred by physicians, nurses, or may self-refer. Vincent Vinciguerra, MD, chief of the division, has led the way for other physicians to refer distressed patients toward support services by preparing a handout for patients of contacts for counseling and/or support services. He then reinforces his recommendation to patients by telling them that many patients and families “have benefited by our Oncology Support Program.”

Most referrals are generated from treatment room nurses who provide support information in the chemo packet and who always contact the social worker when a new patient arrives. In addition, information packets provided to all new cancer patients include an assessment tool that describes the support services offered. Patients can then check off those services they are interested in receiving and drop the survey off in a hanging wall file marked “Social Work Referrals.” The social worker contacts anyone not yet seen in the treatment room. Approximately 25 percent of the program's new and ongoing patients access support services.

One of the most popular supportive services at North Shore University Hospital's Comprehensive Cancer Center is its fee-for-service psychotherapy provided by “clinical” social workers with LCSW-R status. Oncology Support Services offers individual counseling (including interventions to help patients manage fears, anxieties, and related issues that may arise in response to cancer diagnosis and treatment); family counseling; and crisis counseling. For most patients these services are insurance reimbursable, and the patient is responsible only for a nominal co-pay. For those patients not covered for mental health counseling, a fee agreement is decided on that primarily suits the patient.

Editor's Note: When researching our article on complementary services, *Oncology Issues* heard again and again how important staff “champions” are in terms of establishing and growing such programs. And it is often the oncology social worker who spearheads this effort. These trained professionals bring a unique skill set to the multidisciplinary cancer team—offering support to individuals with cancer, families and caregivers of cancer patients, and their provider teammates.



PHOTOGRAPH COURTESY OF ONCOLOGY SUPPORT PROGRAM, BENEDICTINE HOSPITAL.

For patients who are unable to pay, these counseling services are provided free of charge. The proceeds of all fees are deposited into a “Psychosocial Fee Fund,” which enables financial backing to create or sustain program development, purchase literature, provide refreshments, attend conferences, pay for oncology-related services, etc.

For Ampela and Jean Santoro, LCSW, ACSW, the program’s other oncology social worker, education is key. They, along with the vital assistance of additional team medical staff, offer information and referral to all cancer patients, as well as orientation programs for new patients who will be receiving chemotherapy, radiation therapy, or a bone marrow transplant.

At North Shore University Hospital’s Comprehensive Cancer Center, as with many other community cancer centers, support groups fall under the “umbrella” of Oncology Support Services. Currently, cancer patients and their family members have access to approximately 12 specialized or generalized cancer support groups for patients and their caregivers. Support groups are offered one to two times per month. In addition, a “Family Day” is offered once a month for children who have a parent with cancer. The program also offers a smoking cessation series, and hosts the national Look Good...Feel Better and Us TOO programs.

In addition, Ampela and her colleagues have been able to expand services to include many unique wellness-oriented programs and workshops such as:

- Yoga
- Tai Chi
- Meditation classes
- Visualization/guided imagery
- Nutritional workshops
- Exercise programs (*Move, Soothe, and Heal*, post-breast surgery exercise classes with instructors trained in the Ledbed Method®)
- A bone health workshop
- A breast cancer series.

In general, workshops request an optional “donation fee” of \$10, which is tax deductible for participants. Parking fees are waived for all workshops attendees.

Benedictine Hospital’s Oncology Support Program Staff recently gathered to celebrate the graduation of program interns.

More recently, Ampela has begun educating the medical team about the availability of reflexology for inpatients through the Complementary and Alternative Medicine office. This complementary modality involves only foot massage and is performed by a hospital nurse certified in reflexology. Referrals for this service must be physician generated, so Ampela has been motivating physicians to do so at the patient’s request. Feedback from patients has been very positive. Patients have commented “that massage was the best part of my day,” reflecting the importance to patients of the “positive touch” experience and its calming effect on anxiety and/or pain, Ampela said.

Oncology Support Services also reaches out to the hospital’s oncology staff, providing a monthly staff support meeting that includes debriefing, help with relaxation, and other stress reduction strategies. The nurse supervisors set a scheduled “Psychosocial Hour” for treatment room staff approximately every four to six weeks for team cohesion and “compassion fatigue” that is so common in oncology care.

Benedictine Hospital

Nestled in the scenic Hudson Valley, this 222-bed community hospital offers its patients an innovative, expansive oncology support program or what program director Barbara Sarah, LCSW, likes to call, “...a big city program in a small city.”

Sarah’s energy and enthusiasm for the program are evident. Her commitment to complementary services is personal. When Sarah was diagnosed with breast cancer 13 years ago, her cancer experience instilled a commitment to prevention, education, and an abiding interest in complementary modalities that help enhance well-being. Two years after her diagnosis, Sarah retired from her job as a school social worker and came to Benedictine Hospital to run a breast cancer support group. Over the years, Sarah has helped nurture the hospital’s oncology support services never dreaming that the program would become as exten-

A Vibrant Oncology Support Program

Select inpatient complementary modalities offered at Benedictine Hospital include:

- Acupuncture
- Aromatherapy
- An “art cart,” stocked with art supplies, collage materials, journals, and sketch books and manned by a caring volunteer
- Bedscapes®, large photomurals of nature scenes on portable panels with relaxing soundtracks to create a relaxing, soothing bedside view
- Healing Circle Improv group that provides improvisational pieces for patients, their families, and friends in the hospital or at home
- Massage therapy
- Meditation and breathing
- Nutritional counseling
- Pastoral care
- Pet therapy
- Visualization/guided imagery
- Brennan energy work.

Select outpatient cancer patients, supportive services include:

- Complementary medicine discussion groups
- Exercise programs such as Qi Gong, SmartBells® (a sculptured weights exercise program offered in partnership with the Lance Armstrong Foundation), Tai Chi, yoga, and Pilates
- Healing Arts program (painting, calligraphy, music, horticultural therapy, and more)
- The Laughter Café
- The Listening Support Project
- Massage therapy
- Support and educational programs
- Ongoing groups to support women, men, families, teens, children, women with ovarian cancer, and patients with lymphoma.

sive as it has. In fact, Benedictine Hospital recently purchased a house that will eventually become the “Oncology Support House,” a dedicated space for the support program.

Today, Sarah is still part-time to the program, but the support services staff has grown to six—with not more than a total of 1.6 full-time employees. The remaining staff are funded by grants or volunteer to the program. About nine years ago, Sarah started to bring social work interns from nearby universities into the program. Each year several interns commit about 15 to 20 hours a week to the Oncology Support Program.

With this primarily volunteer staff, Sarah oversees a continually evolving program, which offers support groups, a Healing Arts program, and an education program (see box for a list of selected services). The program’s complementary medicine practitioners are all licensed by the state of New York, credentialed by Benedictine Hospital, and trained in working in acute care settings. “Hands on” treatments are performed only with a physician’s orders.

Because the Hudson River Valley area is home to many artists, Sarah said the program benefits from the creativity and support of many talented local residents who volunteer their time to the program activities. For example, members of the Healing Circle Improv Group are all cancer survivors who are trained volunteers with the program. These volunteers visit and perform for patients in the inpatient oncology unit of the hospital as well as making home visits and performing at conferences. Volunteers help produce and distribute the Oncology Support Program’s monthly newsletter. Trained cancer survivor volunteers staff the program’s Nurturing Neighborhood Network, an educational outreach program that links cancer survivors with others in their own neighborhoods who are facing a cancer diagnosis.

“I couldn’t have done it [built this program] without all this help,” Sarah said. “People are grateful for what we give them, and they give back.”

From the beginning, Sarah undertook fundraising efforts to help defray the costs of providing support services. Most of the program’s inpatient and outpatient services are offered free of charge or for a small fee. Insurance may cover some services. For example, insurance may cover massage therapy and lymphedema therapy services.

Recently the program held two fundraising performances of a breast cancer oratorio for chorus and orchestra at a local community college. These two events raised about \$7,000, which was contributed toward renovation of the program’s future home—the Oncology Support House. In addi-

tion, with the help of the hospital’s health foundation, the Oncology Support Program has written numerous grants and received funding from public and private foundations.

The Oncology Support Program also receives donations, and conducts modest fundraising through the sale of hats and fanny packs. Through a variety of fundraising efforts, including an annual dinner-dance, grants, and donations, the Oncology Support Program manages to raise an annual operating budget of between \$30,000 to \$45,000. The grant money pays a substantial amount of the program’s salaries; fundraising supports the Healing Arts Program and its instructors, supplies, and materials.

Sarah uses a number of strategies to continue to grow the cancer services support program. The support program’s monthly newsletter, *Celebrate Life!* helps publicize upcoming activities and events. For example, in spring 2005 “WeCanRow” hit the water. This new group activity was designed for breast cancer survivors with an interest in learning to row with the help of the Hudson River Rowing Association. In addition, many of the cancer support service programs are open to family members and caregivers, as well as staff. ☐

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