

Meeting the Psychosocial Needs of Cancer

A model interdisciplinary program at The Whittingham Cancer Center

“Patients, physicians and other cancer care providers tell us that attention to patients’ psychosocial health needs is the exception rather than the rule in cancer care today.”

Institute of Medicine

Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs “Report Brief” October 2007

Thirty years before the Institute of Medicine report brought national attention to the unmet psychosocial needs of patients with cancers, Norwalk Hospital oncology staff were already working to make emotional, spiritual, and cognitive psychosocial support services available to patients. At that time, Paul Schulman, MD, who was then oncology medical director, established a two-person Cancer Support Team—consisting of one nurse clinician and one social worker. Today, our Support Team is an interdisciplinary group including three masters-prepared advanced oncology nurse clinicians, a licensed clinical social worker, a licensed family therapist, two research nurse practitioners, spiritual care advisors, and a dietitian. Funding for the Cancer Support Team comes from the hospital budget and donated funds. Psychosocial services at The Whittingham Cancer Center are provided free of charge to cancer patients.

Mary Ellen Loncto, RN, MSN, AOCN, is the team’s manager, dividing her time between a myriad of administrative issues and clinical practice. Melinda Brockwell, APRN, holds a national certification in pain management and focuses her practice on the management and treatment of pain. Bridget DeBartolomeo, RN, MSN, OCN, specializes in palliative care and hospice issues. Research nurse practitioners, Linda Versea, APRN, and Jennifer Long, APRN, are devoted to enrolling and monitoring patients in any of the 25 to 30 open clinical trials available to patients. The team’s social worker, Nancy Gennaro, LCSW, and family therapist Michelle Dailey, LMFT, provide professional counseling to patients, families, and groups. The family therapist is proficient in Spanish, has expertise in working with children, and is also a notary who can expedite the process of advance directives. All members of the Cancer Support Team have years of experience and education in oncology, enabling them to quickly and efficiently zero in on and assess patient and family problems.

Our team’s goal? To best support patients and families throughout the cancer experience so that medical care can be optimized while the patients’ psychosocial needs are

managed. We are confident this support team model is one that other community-based cancer programs can successfully replicate and implement.

Our Team at Work

The Cancer Support Team’s offices are located in the middle of The Whittingham Cancer Center, making them easily accessible to both medical oncology and radiation patients. Similar to many other hospitals, medical oncology services, including a chemotherapy infusion suite, are provided by



*Crafting Ways to Cope,
kids support group*

Patients

by Mary Ellen Loncto, RN, MSN, AOCN

a private physician practice that leases space from the hospital. However, the physical layout of The Whittingham Cancer Center maximizes access to the Cancer Support Team. When a patient or family member is in “trouble,” help is available, usually within minutes. This quick access can be especially important when an oncologist informs a new patient and his or her family about a cancer diagnosis. The physician can immediately bring the often devastated and overwhelmed family to a support team member, who performs an assessment and sets up a plan for ongoing care.



PHOTOGRAPH COURTESY OF THE WHITTINGHAM CANCER CENTER

“As a radiation oncologist, I can prescribe the most appropriate treatment plan, but I need someone else—a team of professionals—to handle the emotional, social, and financial issues that arise. Our Cancer Support Team is exquisitely attuned to the needs of cancer patients and their families. The team intuitively appreciates the environment in which the newly diagnosed patient is in—an environment of change, fear, and uncertainty. When patients are helped with emotional aspects, their outlook begins to change, hope re-surfaces, and their treatment course is smoother.”

Pradip Pathare, MD
Medical Director
Director of Radiation Oncology
The Whittingham Cancer Center

The quick response of the Cancer Support Team can begin to restore the patient’s and family’s sense of control.

Access to the Cancer Support Team occurs in many ways. In addition to referrals from medical and radiation oncologists, referrals come from nurses and medical assistants, radiation therapists, case managers, and home care nurses. But perhaps the most rewarding referrals come from the patients themselves—word-of-mouth referrals from cancer patients and families that have benefited from the program. The underlying reasons behind these referrals vary as greatly as the patients themselves and can include:

- Anxiety
- Depression
- Severe pain
- Treatment side effects
- Financial concerns
- A need for additional and complex patient education
- Advance directives
- Childcare needs
- Strategies for communicating with physicians

Cancer Support Team services are also available when a Norwalk Hospital employee, or an employee’s family member, is diagnosed with cancer. This opportunity for supportive care only serves to strengthen the real sense of family and support that many long-time—and even short-term—employees feel toward the hospital.

Underserved members of the community who are diagnosed at Norwalk Hospital through the Connecticut Breast and Cervical Cancer Early Detection Program are also referred to the Cancer Support Team for financial counseling, education, and ongoing support. These services are

“Too often we have to deliver devastating news. No matter how gently we try to soften the blow, more support is needed to help the patient and their family. That’s when we call in the support team—immediately, not tomorrow or next week. This team is there, on the spot, to soften the blow with caring support and, of course, tissues and hugs. Now patients know how it works—families are met, they set up appointments, and come in for counseling. It’s all programmed for the patients and that’s what helps them survive.”

Richard Frank, MD
Medical Oncologist
The Whittingham Cancer Center

performed by the Cancer Support Team’s case worker, who oversees the state-funded program that provides free screenings for women who lack insurance or the ability to pay.

Inpatient Support Coordination

The Cancer Support Team is available to patients and families at many stages of the illness, particularly at times of disease progression or unexpected admission to the hospital. About 600 oncology inpatient admissions occur each year with an average of 10 to 15 oncology inpatients in the hospital on any given day. An oncology inpatient census is compiled and updated daily for distribution to all essential staff.

Each inpatient is followed by a nurse clinician and a psychosocial professional who provide assessment, care coordination, and follow-up care. This “double-teaming” works well: the nurse provides education and helps manage treatment-related side effects, while the psychosocial team member manages the emotional and social aspects of care. Together, this team leads family meetings where critical decisions are made related to discharge, childcare needs, change in treatment plan, and hospice arrangements.

Through contractual relationships with several hospice agencies, patients can receive hospice care at home, in the hospital, at the local inpatient hospice residence in Stamford, Connecticut, or at the hospital/hospice in Branford, Connecticut. To further the goal of providing seamless care, the support team has regularly scheduled meetings with the hospice nurses and social workers. Here, too, patient and family issues are presented and the team approach is critical.

Another key component of the Cancer Support Team is providing care coordination and facilitating communication among care providers. Every Monday at noon, the multidisciplinary cancer care team gathers in the Cancer Center’s conference room for interdisciplinary rounds on current inpatients. Essential participants include the oncologist who was on call the prior weekend, the inpatient unit case manager and nurse manager, the physical medicine and rehabilitation manager, the inpatient dietitian, the radiation medicine nurse, the Transfusion Suite nurse manager, and the Cancer Support Team. At the meeting, all inpatients are presented and discussed. This format allows key players to appreciate patient and family issues and decide on the need for additional resources. As a result of the meeting, discharges occur sooner and necessary community resources are utilized.

Barriers to Psychosocial Care

Literature points to two main reasons for underutilization of support services: 1) physicians do not refer the patients and 2) patients do not avail themselves of the services until very late in the cancer experience. At The Whittingham
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Support Groups

Because a diagnosis of cancer dramatically alters a person’s life, individuals need to learn to adapt to this life-changing situation. Failure to adapt can result in needless patient and family suffering and potentially affect the outcome of the illness. Many patients have found this adaptation to illness occurring in the context of group support. The Cancer Support Team facilitates the following support groups.

Patient and Caregiver Support Group

This long-standing support group meets weekly at the Cancer Center with attendance averaging more than 20 people per meeting. Due to an increased number of participants, a second support group was added in June 2008.

The Patient and Caregiver Support Group is co-facilitated by a social worker and nurse clinician. A unique feature of the group is that every other week the group splits into two groups: caregivers meeting with the social worker and patients meeting with the nurse. Group participants requested this format, which allows for more freedom to discuss certain issues and for strong bonds to develop among group members. This practice is particularly advantageous for caregivers when a patient is hospitalized or when a patient’s condition is deteriorating. Since the benefits of this group are well known and no other support group like this exists in our area, cancer patients are being referred to the group from neighboring cancer centers. The Patient and Caregiver Support group is a safe haven for people to express their fears among others who understand their feelings.

Breast Cancer Support Groups

Two support groups are available for patients with breast cancer: one for newly diagnosed patients and a survivors’ group for those who have completed treatment. Both groups are facilitated by a clinical nurse specialist in the Smilow Family Breast Health Center. Participants appreciate the educational information they receive and the chance to meet others who are “in the same boat as I am.”

Crafting Ways to Cope: Kids Group

Now in its third year, this support program for children of patients with cancer is a collaborative effort between

“Comprehensive care in a structured and medically supervised setting is of enormous help to patients going through the ordeal of treatment. Having a multidisciplinary team of professionals and support programs readily available enables the oncologists to address the multiple needs of patients in a timely manner.”

Richard Zelkowitz, MD
Breast Oncologist
The Whittingham Cancer Center

PHOTOGRAPH COURTESY OF THE WHITTINGHAM CANCER CENTER



Crafting Way to Cope banner leads The Whittingham Cancer Center’s *Walk This Way with Us* fundraiser.

The Whittingham Cancer Center and Cancer Care, Inc. The monthly program is for children ages 5-12 who have a parent diagnosed with cancer. Each session is offered as a free two-hour workshop in which families dealing with cancer come together with others in the same situation. A major goal of the program is to help children feel safe and supported as they explore questions, concerns, and fears. Many parents report that a positive outcome has been to bring cancer “out of the closet” and into the normal flow of family communications. A unique offering of the program is a concurrent parents’ group in which parents can learn coping skills, communication strategies, and gain knowledge to help guide their children through the family’s cancer experience. Kid’s Group sessions are designed to be fun and interactive, and always include pizza dinner for all.

In 2007, the Cancer Center presented six *Crafting Ways to Cope* groups beginning with a special Family Night in September followed by a series of Kid’s Group sessions, which ran monthly in the fall and spring. The Cancer Support Team’s social worker facilitates the concurrent parents’ group, which meets in a nearby conference room at the same time as the children’s group. A similar series was held in 2008.

The Kid’s Group sessions, facilitated by the Cancer Support Team’s family therapist and a Cancer Care social worker certified in art therapy, uses various crafts and interactive games to engage the children in expressing their

feelings and sharing stories about cancer in their family. For example, one activity involved the children creating “thumb-buddies” from their own thumb-prints, naming all the people who love and care about them. Other activities have included “worry cups” and “comfort pillows” to help “hold” the children’s many worries and feelings about the cancer. And for the third year in a row, the Kid’s Group participants created a colorful *Crafting Ways to Cope* banner, which they proudly displayed as they led The Whittingham Cancer Center’s 5th spring fundraising event, entitled *Walk this Way with Us...* More than 1,000 participants followed the children at this event.

Bereavement Support

The weekly Bereavement Group, co-facilitated by a nurse clinician and family therapist, offers ongoing support for those who have lost a loved one. This open group of 6–12 people provides an opportunity for members to share their grief experience in an atmosphere of mutual support. Participants forge new friendships and learn ways to adjust in their life without their loved one.

The support and bereavement groups’ leaders have benefited from bi-weekly supervision sessions with one of the leading psychiatrists on staff at Norwalk Hospital. Frank Hamilton, MD, has offered this service free of charge for the past 30 years and helped the leaders with difficult group issues.

Staff Support

A monthly staff support group, co-facilitated by the nurse clinician and family therapist, provides a place for hospital staff to express their feelings and concerns about providing care for oncology patients. Every December, the Cancer Support Team invites the oncology staff and volunteers to a Memorial Service to reflect on the work they do and to honor the patients who died during the year.

In addition to their work with patients and families, the Cancer Support Team’s nurse clinicians promote community-wide cancer prevention and early detection, hospital and community staff education, and serve as consultants in matters of oncology nursing. 📖

“When you learn that you or a family member has cancer, the journey begins. The care and support you receive during this journey are important factors in helping you cope with the changes along the way. Our patients are relieved to know that they do not have to face this disease all alone. When patients know there is a team of professionals to lean on everything becomes much easier.”

Nancy Gennaro, LCSW
Social Worker
The Whittingham Cancer Center



PHOTOGRAPH COURTESY OF THE WHITTINGHAM CANCER CENTER

Members of the Cancer Support Team at The Whittingham Cancer Center.

Cancer Center, we have overcome these two obstacles. Our physicians recognize the need for psychosocial support, and they appreciate the professionalism and responsiveness of the team.

The Cancer Support Team pro-actively reaches out to cancer patients and their families. This year, the team developed a system to ensure that each newly diagnosed cancer patient receives information about the available support services. A folder with brochures describing the cancer center’s treatment options and support services is handed out at the patient’s first oncology visit. The information packet includes a needs assessment, which patients are invited to complete, indicating a request for more information. Within a few days, the appropriate member of the Cancer Support Team calls or emails the patient to follow up.

So, for example, if a referral is related to financial challenges, the team’s social worker is generally the point person. She assists cancer patients with a variety of financial needs related to medications, rent, transportation, and childcare. The social worker is knowledgeable about community agencies and other resources to help those in need and has often made the difference between a patient’s ability to receive cancer treatment or not. This initial needs assessment approach has proven quite successful, allowing more patients to avail themselves of the support programs early in their cancer journey.

In addition to meeting patients at the time of diagnosis, the Cancer Support Team interfaces with patients at other times and places throughout their cancer journey. Team members take care to meet each patient on his or her own terms—some patients want a lot of support while others are more reticent and private. This approach means patients can decide if and when they wish the team’s intervention. The Cancer Support Team’s objective is to make sure that all patients know that help and support is available whenever they are ready.

For many community cancer centers, money can be a barrier to offering comprehensive psychosocial services. At The Whittingham Cancer Center, Cancer Support Team salaries are funded through the hospital budget and donated funds. The research nurse practitioners are paid through a research fund, which receives sponsor payments and donations earmarked for clinical research. The social worker and family therapist are paid from donations given specifically to support the psychosocial services for cancer patients. An additional large funding source is The Whittingham Can-

cer Center’s annual fundraising walk. Now in its fifth year, the walk has raised almost one million dollars for cancer programs, personnel, and technology.

The Whittingham Cancer Center’s Cancer Support Team does not charge for its psychosocial services. While the cancer program administrator has periodically investigated fee for service—especially for counseling services—the time and personnel required to set up billing, charging, and fee collection would be a costly endeavor in itself and would impact patients who could not afford such services or whose insurance would not cover such services. Our experience is that many cancer patients and family members make donations to The Whittingham Cancer

“From the moment I drop off my car, through the very brief time in the waiting room, to treatment, I have been in the company of people who work in perfect harmony and love what they do. I have been treated—on time—41 times by providers who know how to treat patients. They are like ‘family’.”

Cancer Patient
The Whittingham Cancer Center

Center in appreciation for the services they have received from the support team. And the Cancer Support Team is most grateful for this consistent flow of donations over the years.

We know, however, that there is always room for improvement and/or expansion. Although our psychosocial services are comprehensive in scope, the Cancer Support Team is continually evaluating its programs and adding new programs. For example, at our surgeons’ request, plans are underway for the team to receive referrals for people diagnosed with cancer at the time of surgery. As always, our goal is to continue to grow and evolve to meet the changing needs of our cancer patients. ☐

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