

GIVING PATIENTS A "GOOD DEATH"

"Annie" was a 41-year-old mother of three hospitalized in early 2000 with advanced breast cancer. She knew she was dying and wouldn't be around to see her "angels" grow up. She pleaded with the nurses on the oncology unit at St. Joseph Hospital in Nashua, NH, to let her go home, where she could spend her remaining days with her children. "Help me make it work," she asked them.

At the time, there was no formal end-of-life care program in place at St. Joseph, a fact presenting formidable challenges to coordinating Annie's pain management and symptom control and attending to her emotional and spiritual needs in the home setting. Moved by this patient's request, however, a multidisciplinary team came together, with the blessing of the hospital's ethics committee, to meet the problems involved in fulfilling her request. This was the genesis of St. Joseph's Circle of Life Palliative Care/End of Life Program.

Now in its fourth full year, the Circle of Life has to date provided compassionate end-of-life care for nearly 400 patients and their families, increasing the number of patients served by more than 30 percent from one year to the next. It has earned recognition for quality from New Hampshire's government. And during a recent visit by representatives from the Robert Wood Johnson Foundation, it was lauded as the youngest but most comprehensive end-of-life

A New Hampshire Facility Describes the Development of Its End-of-Life Care Program

BY NANCY MULVIHILL

care program in the state.

What makes the Circle of Life so remarkable is that it began as—and largely remains—a "virtual" program. Rather than being confined to a specific unit or location in the hospital, the program is a philosophy of caring; a consult can be initiated by anyone in the organization who feels it is warranted. The program has a core team comprising a medical director, nurse leader, program coordinator, social worker, hospice liaison, professional ethicist, and chaplains. But only the social worker currently is a dedicated full-time employee (FTE). Most other team members hold positions elsewhere in the hospital, devoting time to the Circle of Life Program in addition to their full-time jobs. And perhaps most remarkable of all, the program was launched without any start-up funds.

Helping patients walk their final journey with dignity, peace, and compassion, as well as supporting their loved ones throughout the process, is an integral part of being a mission-driven health care organization. For hospitals interested in initiating or enhancing end-of-life care programs of their own, the St. Joseph Hospital program provides valuable information and inspiration. Here is a closer look.

GETTING IT OFF THE GROUND

"St. Joseph's previously had a palliative care program in 1991, but with financial pressures and downsizing at the time, the hospital was unable to sustain it," explains Sr. Carol Descoteaux, CSC, PhD, who joined the hospital as vice president for mission integration and ethics in 2000. "When the nurses brought Annie's case before the ethics committee [in 2000], it was as if God was saying that the palliative care program was meant to be."

With the support of the ethics committee and a strong physician champion in Donald B.



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McDonah, MD (a family practitioner board-certified in palliative medicine and a founding member of the Canadian Palliative Care Association and the New Brunswick Palliative Care Association), Sr. Carol took the idea of revitalizing the palliative care program to the hospital's senior management and the board. They were very receptive.

"It just made sense," says Peter Davis, St. Joseph's CEO. "This area [of end-of-life care] can be very abstract. The team created an objectivity and methodology, linking like services and disparate clinical functions, with people dedicated to keeping patients alive and others helping them let go. It brought continuity to the process of dying, and a way to deal with critical issues in a way everyone could understand. It's holistic because it takes the process of dying, coordinates the patient's care, and brings resolution to things often left unstated. It allows the patient to have a degree of control. And it evaporates some of the high-tech coldness that can come between caregivers and patients."

"There also was an amazing confluence of events at the time that brought national attention to the need for end-of-life care," Sr. Carol recalls, referring to the appearance in the late 1990s and early 2000s of phenomena such as Mitch Albom's book, *Tuesdays With Morrie*, and Bill Moyers' PBS special on death and dying.¹ Closer to home, in 2000 Covenant Health Systems, Lexington, MA, the regional health care system with which St. Joseph Hospital is affiliated, held a daylong seminar on pain management. In June of that year, Covenant also sponsored the attendance of three staff members at a conference on coordinated care for advanced illness, based on the FairCare program for peaceful dying developed by Daniel R. Tobin, MD, at the Stratton VA Medical Center, Albany, NY.²

"We learned that palliative care is just a small part of a much bigger picture," Sr. Carol says. "We needed to think more broadly and, if we were to be faithful to our ethical and religious directives, create a comprehensive end-of-life program."

The first task was to create a strategic plan. "Through the experience with Annie, we learned that things can get done, and we could work as a team," says Dr. McDonah, who took on the role of the program's medical director. Before coming to St. Joseph 10 years ago and building a busy family practice, he had run a palliative care unit in an 800-bed tertiary care hospital in Canada. "But we needed to decide what our program would look like. It could either be a separate unit, with designated beds, or a consult service. Given the reimbursement climate, a consult service made

the most sense."

Time and attention also were devoted to developing the fundamental tools needed to administer the program and evaluate its effectiveness. These included a consult form, a questionnaire to measure patient/family satisfaction, and a database to capture all appropriate clinical and demographic information and measure outcomes.

In addition, the program established an advisory council, made up of representatives from the core team as well as members of the community. Joyce Arel, a former hospital trustee, was a founding member of the advisory council and still serves on it today. "We were there as a lobbying force to get support for the team," she recalls. "But it wasn't hard to sell. Its incredible value in serving the hospital's mission sold itself."

A FULL RANGE OF SERVICES

From the outset, the Circle of Life program was intended to offer a full range of medical, psychosocial, and pastoral services to address an individual's unique physical, emotional, and spiritual needs and foster a positive dying experience. Patients are referred to the program from virtually anywhere or from anyone within the St. Joseph organization, and consult requests are seen by the medical director and nurse clinician, usually within 24 hours. Core team members see patients and family members as their individual needs require. Team conferences are held weekly to review the status of patients involved in the program, and team members are in contact daily via phone and e-mail.

"It's the goal of the team to see the patient as early as possible, ideally at diagnosis," explains Kim Leets, RN, the program's original coordinator. "If we can get to patients early on, we can help them understand their disease and treatment options, and help them make decisions about advance care planning and directives before it's a crisis situation." In fact, every inpatient at St. Joseph is approached about advance directives upon admission, regardless of diagnosis.

Leets, who has been at the hospital for 27 years, remembers what it was like when there was no formal end-of-life care program. "Now, with a cohesive team, we can identify issues, pull together resources, and keep everyone on the same page throughout the entire process," she says. These resources include advance care planning, pain and symptom management, referral to appropriate care settings outside the hospital, hospice care, and pastoral counseling. In addition, Circle of Life patients are given access to complementary alternatives including guided meditation, Reiki, music therapy, acupuncture, and hypnosis.

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"At the patient's request, we'll even arrange family meetings in the hospital that include the doctors, nurses, physical therapists—everyone involved in that patient's care," says Mary Lynn Lammers, MSW, the program's current manager (and only dedicated FTE). "We can exchange information so that the goals of care are clear, the patient's wishes are known, and everyone understands what to anticipate. Patients are often surprised that we can make this happen. But illness itself is so isolating that when you add a lack of information, it creates fear. So communication and collaboration are vitally important."

Because family and loved ones are affected by the dying process, the Circle of Life program reaches out to them as well, hosting three professionally facilitated bereavement support groups throughout the year, following up with personalized bereavement letters six and 12 months after a loved one dies, and holding memorial services twice annually. A monthly Empty Cradle support group also is held for bereaved parents.

CARING FOR THE SPIRIT

A key Circle of Life component is ministering to the spiritual needs of both patients and families. The core team includes two chaplains: Theresa (Terri) Neault, who works with inpatients, and Deacon John Martin, who visits patients outside the hospital. Both make it clear that, although St. Joseph is a Catholic facility, they have no religious agenda when dealing with patients at the end of life.

"When someone is dying, we're not concerned with their religious beliefs, but with who they are spiritually with their God or higher power," says Neault. "It's about the journey, not religious tradition. Spirituality is bigger than any organized religion. My role is to be present to people and provide the support they need. The most important part is to listen with the ear of the heart to what's being said, or not said, and validate who they are. Whether Christian, Hindu, Jewish, or Muslim, they appreciate having a person there to listen, pray with them, and hold their hands."

Neault is herself a cancer survivor. "I sometimes share my story when it's appropriate," she says. "It gives me some common ground and credibility with cancer patients. And it makes it easier to speak to the experience they're living through."

Martin came out of retirement to work three days a week with the Circle of Life program, calling on patients who are at home, in nursing homes, or hospice. "When someone says to me, 'I'm not Catholic,' I tell them it doesn't matter. I'm not a salesman for religion. I help people come to terms with their mortality, to feel good about themselves, and live well until they die. It's

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a religious experience without being religious.

"You find out what beautiful spirituality people have," he adds. "Their faith and hope grab you. You're on holy ground with people at the end of life. It's a very special place, and they invite you in."

EDUCATION AND COMMUNITY AWARENESS

Team members are quick to acknowledge that the program's effectiveness depends on education and community awareness—getting the word out about the program and its resources for patients, families, and caregivers. "The education piece is huge," says Debbie Goodwin, RN, who functions as the hospice liaison for the program, and helps identify what's needed when patients are discharged to home. "We do a lot of outreach to residential care facilities, nursing homes, and the medical staff to let them know about the resources available through this program." Team members have given presentations on such topics as hydration and nutrition and advance care planning. Dr. McDonah attends oncology rounds at the hospital to give palliative care input. Circle of Life makes brochures about the bereavement support groups available at area funeral homes.

The outreach is working. Not only have overall referrals increased each year; they now come from a wider range of physicians. "While the majority of consults continue to be terminal oncology patients, we're now seeing patients with end-stage renal, respiratory, and cardiac disease, as well as end-stage Alzheimer's disease," notes Monique Savage, who maintains the Circle of Life database and coordinates advance directives. The former program coordinator for palliative care/advanced care planning at St. Joseph, she is now coordinator for mission services.

Doesn't such visibility for death and dying create a public relations problem for the hospital? "Some hospitals won't acknowledge that people die," Dr. McDonah responds. "They have their heads in the sand. You can have the most fantastic oncology program, but patients still die. [St. Joseph's] leadership isn't frightened of having this program perceived as a negative. They realize that its mission and commitment are in keeping with the philosophy of the hospital."

"While I don't want us to get the image that [caring for the dying] is all we do, I'm comfortable that it's part of the overall capabilities of the organization," says Davis, who notes that St. Joseph was recently included in Solucient's "100 Top Hospitals: Benchmarks for Success" program as one of the top overall achievers in the industry.

A GROWING NEED

According to the Center to Advance Palliative Care, only a handful of palliative care programs

existed five years ago.³ Today, however, more than 800 hospitals in the U.S. provide palliative care services to their patients (17 percent of community hospitals and 26 percent of academic health centers). This growth trajectory is likely to continue.

"As baby boomers get older and face their mortality, they're going to demand excellence in end-of-life care," says Jean Montana, RN. Nurse manager on St. Joseph's Oncology Palliative Care unit until 1996, she is now director of quality and resource management. The Circle of Life program is under her purview in the hospital's organizational chart. "We've lived well and we want to die well," Montana says, voicing contemporary attitudes. "We want to know our choices, be prepared, and be supported. We want to make decisions at an earlier stage when we're capable, not when we're in crisis. And we don't want to ricochet through the health care system and receive fragmented care."

"It's the wave of the future," Dr. McDonah adds. "The Joint Commission on Accreditation of Healthcare Organizations wants to see end-of-life care in both long-term care and acute care settings; it's one of the benchmarks they're looking at. And it's just the right thing to do."

QUANTIFIABLE BENEFITS

"This type of program is not just a 'warm-and-fuzzy,' although it takes a while to prove that," says Sr. Carol, noting that outcomes measurement is an important part of the St. Joseph program. One of the outcomes measured is patient and family satisfaction. "We've compared patients in the program to those who weren't, and found that people in the program are much happier with symptom and pain management," says Savage, the program's database manager. "Patients and families in the program also are happier with their quality of life, and with the spiritual/pastoral care received."

"We also know we're having a positive effect through the testimonials we receive and through increased donations to the 'Tree of Life,'" Savage adds, referring to a fund built through contributions received from families and friends in memory of loved ones who have died. The fund is symbolized by a memorial that sits near the facility's main entrance. The memorial was donated by a hospital staff member whose late wife was cared for by the Circle of Life program. Called the Tree of Life, it is shaped as a tree with multicolored leaves, the colors signifying the different amounts of money donated to the fund. The money is used for supplies, education, and other program needs.

"Families who have been part of the program want to give back," says Lammers, recalling a

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woman who, since her husband died, visits terminally ill patients in the hospital. The woman is accompanied by her dog, which has been certified as a "therapy dog," an animal whose presence ill people find comforting.

Physicians are realizing that the program helps them, too. "For doctors who have a hard time with end-of-life issues, the team is a great resource," says Leets. "They realize they don't have to deal with a dying patient and his or her family alone," adds Goodwin.

The program also has bottom-line benefits. "There's a tremendous cost-avoidance aspect to what we do," Goodwin says. "With the team's expertise, we can identify what the patient really needs, and often avoid unnecessary and expensive interventions like blood tests, MRI, or CT exams. And because they're getting the most appropriate level of care, we often lessen the need for hospitalization."

The team hopes to quantify the cost-effectiveness of the Circle of Life program more thoroughly in the future. "We can speculate about costs avoided," Savage says, "but now we're looking at how to quantify that, to document how we're saving money and perhaps gain more reimbursement." Currently, only Dr. McDonah is compensated for consults.

TO THE "NEXT LEVEL"

Now in its fourth year, the Circle of Life program is in transition. Team members realize it's time to take the program to the "next level," to make it a more formal and less "virtual" operation. An important move was positioning the program under Montana, who reports to William Steffen, MD, the hospital's vice president for medical affairs. "It gives the program a whole new level of validity," Montana says, particularly with the physicians on whom the program depends for referrals.

"If we want the program to be sustainable for the long term, we also need more dedicated FTEs. We recently posted a position for a full-time nurse practitioner. This person can do inpatient assessments to relieve Dr. McDonah, who now sees patients in the early morning or in the evening, outside his regular practice."

The team also wants to expand its focus to encompass more advanced illness planning. "Now we generally see patients in their last eight to 12 weeks of life," Savage says. "Our goal is to start looking at patients' needs 18 months out."

ADVICE TO OTHER HOSPITALS

What advice do the Circle of Life team members have for other hospitals considering such a pro-

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gram? "Enlist a champion who's dynamic, gung-ho, passionate, and respected in the community and the hospital," urges Dr. McDonah. "Also, get a very good administrative person, since passion and organizational skills don't often go together. And look at care for the caregiving team, to prevent burnout."

"Identify key people to serve on the team who represent various disciplines but share the same philosophy of care," advises Lammers. "They must be comfortable discussing end-of-life issues and have no agenda. The level of support from the top down must be generated and sustained. And education is key—you must engage the community. End-of-life issues aren't black-and-white, and it's not cookbook medicine. There's no algorithm for end-of-life care; you have to work with patients and their families on an individual basis. And meet them where they are."

"It's tough work," Lammers says. "I go home emotionally exhausted. But I wake up the next day and I want to be here." □

NOTES

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