

AWARD WINNER

ST. MARY'S HEALTHCARE SYSTEM
FOR CHILDREN

Bayside, New York





St. Mary's Healthcare System for Children has a long track record in palliative care, becoming one of the first health care organizations in the country to establish a home care program 20 years ago, and a 10-bed inpatient palliative care unit a year later.

But what makes the system even more remarkable is its ability to change with time and experience. By the mid-90s, the organization found that the inpatient unit was no longer the best model of care. Children were living longer; parents missed interaction with other parents; and children knew what a transfer to the top floor's palliative care unit meant — they wouldn't be going home.

So St. Mary's leaders were willing to change. They closed the inpatient unit and went to an integrated bed model, offering palliative care throughout the hospital. And they didn't stop there. They expanded palliative care to patients who were not at the end of life, but were suffering life-limiting diseases and could benefit from specialized, supportive care such as counseling and pain control.

"We broadened our horizons and tried to imbue the entire health care system with knowledge and understanding of palliative care," explains Medical Director Eddie Simpser, M.D.

Carrying out a more sophisticated, nuanced approach that offers palliative care at earlier stages of the disease process requires a major educational effort for medical professionals both on the staff and in the community. "It's an ongoing process, and it's never ending," Simpser explains. "There's staff turnover and growth. And people either forget or don't buy into it the first time around." The organization appointed a staff member whose job is only to deal with palliative care delivery and staff education.

To expand the concept of palliation "upstream," St. Mary's developed palliative care pathways and a three-level system of care that introduces palliation earlier, such as when a chronic illness becomes progressive, causing loss of function. "The earlier that families and kids get palliative care, the less intense the need for services at the end of life, and kids can die either at home or in a non-invasive, home-like setting, surrounded by loved ones, rather than in the ED or ICU," says Eileen Chisari, vice president and administrator.

St. Mary's leaders believe their palliative program is applicable elsewhere and they're making efforts to share what they've learned with other health care organizations, particularly nursing homes and children's hospitals. They were invited by the New York State Department of Health to speak to nursing homes about end-of-life care and have lectured to other pediatric programs. "The uniqueness of our approach is really a continuum where we can take a child with moderate medical needs as an inpatient, then transition their care to our home program for an extended period of time, rather than having them remain in the hospital for months," says Simpser.

Pediatric pain management has also been a priority at St. Mary's, where an "ouchless" environment was created in 1997. The pain management program works on the philosophy that "no pain is okay" and assesses the presence of pain before the child expresses it. St. Mary's caregivers learned that children tend to underreport their pain because they want to please the adults caring for them, explains Chisari. "We have to use signs and scales for nonverbal cues, so we look at their faces, affect, and body language," she says. Children and particularly teens are taught that they

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INNOVATION HIGHLIGHTS

PALLIATIVE CARE PATHWAYS

EARLY INTERVENTION PROGRAM FOR INFANTS

DEVELOPMENT OF PEACEFUL DYING PLANS WITH FAMILIES

not only have rights as patients, but also responsibilities. “They need to partner with us in managing their pain,” Chisari says. “We talk about their responsibilities in very concrete ways to help us manage their pain.”

One of St. Mary’s major goals, Chisari says, is to continually work harder to “hear the voice of the child.” Sometimes, she says, an adolescent at the end of life may have different ideas about how to spend that time than the parents. “We become the facilitator, the mediator of discussions between a child who is dying and the parents who have their own desires,” she says. “We’ve relied heavily on our ethics committee, which has become much more of a real, living part of the organization.”

St. Mary’s has remained open to new ideas to help children feel more empowered in their illness. Classes in tai chi and yoga teach them to focus, using inner strength to get through difficult or painful times. “The *Kids Kicking Illness* martial arts program trains kids to harness their inner light as a source of strength,” explains Alice Olwell, project director for complementary care. “They use their punching and kicking skills to hit a focus bag that they have labeled as their disease or negative feeling. It is really empowering, and we see the kids blossom and grow in self esteem as they learn to use their own power to heal themselves.”

Integrative modalities including energy work were incorporated into inpatient care by Olwell. Offering Reiki and therapeutic touch to children with life threatening illnesses provides another source of comfort and relaxation and enhances the traditional therapies they are already receiving. Rehabilitation therapists find the children more relaxed after an energy treatment. Parents can also take advantage of these therapies.

Another unique program component is St. Mary’s Vehicular Access Program, which provides transportation and an escort for health care professionals to visit sick children in high-risk or difficult-to-serve neighborhoods who otherwise couldn’t be accepted into the home care program. The VAN program serves 280 patients a week with eight vehicles.

At the Bayside campus, there is also a public school on site, serving children kindergarten through 12th grade, along with a preschool. Attending school gives children the opportunity to continue their development and peer socialization for as long as physically feasible.

Palliative care continues for the family beyond the child’s death through a bereavement program that involves at least three contacts by phone or home visit during the first six months afterwards. “We like to say that following acute care, St. Mary’s is the rest of the story,” Chisari says. •