

FOOTPRINTS

SSM CARDINAL GLENNON CHILDREN'S HOSPITAL

St. Louis, Missouri

At a recent fundraiser for the FOOTPRINTS program, the mother of a child who had died only a month earlier asked to speak to the group. She told the story of her baby, who had been expected to die at delivery. A pediatrician referred the family to SSM Cardinal Glennon Children's Hospital, where FOOTPRINTS mobilized.

"Everyone, including the parents, knew that the baby was going to die soon. Our role was to support the family's decisions about care and help them be parents to their baby," says Mary Ann Collins, program director for FOOTPRINTS. "We were here to say, 'What you're doing is medically and ethically appropriate.'"

FOOTPRINTS staff provided emotional and spiritual support during the baby's eight months. The baby died at home, in her mother's arms. FOOTPRINTS staff went to the wake and spoke at the funeral. "The family called the funeral a going-away party," says Collins. "They taught us that life for this child was a gift. They helped us remember that it's not about what we think is a good dying process — it's about what the family feels will make them most peaceful."

That level of involvement, compassion and skill is what FOOTPRINTS is about. With its staff available at all times to support the family and with its focus on caring for the child and family physically, emotionally, and spiritually, it coordinates direct care by bringing together physicians, nurses, clergy, educators, volunteers, researchers, and community agencies. Because the program coordinates but does not directly provide care, the low-cost, high-value approach makes FOOTPRINTS an intriguing role model.



Much of its momentum comes from the intense commitment of its staff and volunteer advisory committee. FOOTPRINTS gave itself a jump start by adopting best practices identified in national studies and publications, while also creating its own innovative approaches.

One of FOOTPRINTS' innovations is its use of a continuity physician. In focus groups, FOOTPRINTS staff learned that parents often felt lost, because there seemed to be no one person in charge to whom they could turn for guidance. So, FOOTPRINTS identifies a continuity physician — usually a tertiary-care specialist — to be the family's central point of contact and to coordinate all care-related needs.

FOOTPRINTS also has gone beyond the conventional in making connections with emergency medical services, police, and other community resources. FOOTPRINTS staff identifies all EMS districts serving children discharged from the hospital, notifying them of families' wishes regarding resuscitation and other life-prolonging procedures. In addition, FOOTPRINTS distributes the family's written, advance-care plan to

emergency medical personnel, medical equipment providers, police, funeral directors, and coroners.

"The response has been remarkable," says Suzanne Toce, MD, FOOTPRINTS' volunteer medical director. "To date, 100 percent of EMS providers have honored the plan, and many have asked for approval to meet the families in advance."

Being part of a university affiliated, tertiary-care facility is an obvious plus, and FOOTPRINTS has made the most of it. Collaborating with St. Louis University's School of Public Health, FOOTPRINTS held focus groups with 54 health care professionals and conducted a community needs assessment with input from nearly 200 physicians, nurses, and home care/hospice staff. Many aspects of FOOTPRINTS directly reflect the needs identified.

Research and staff education continue to play key roles for FOOTPRINTS, and Mary Ann Collins offers this advice to others: "Educate and involve everyone in what you're doing, from allied health and lab to maintenance and security. The results can be surprising. When one of our children couldn't sleep at night, he'd go and sit with our security guard. Every morning, when the boy's Dad came to visit, that was the first person he'd ask about how his son was doing."



INNOVATION HIGHLIGHTS

USE OF COMMUNITY FOCUS GROUPS TO SHAPE SERVICES

CONTINUITY PHYSICIAN TO COORDINATE CARE

COORDINATION WITH EMS