

PEDIATRIC PROGRAM
HOSPICE OF THE WESTERN RESERVE

Cleveland, Ohio

Cleveland's hospital marketplace is as competitive as it gets. But all that gets set aside when it comes to improving care for seriously ill children.

In a unique physician-centered model, doctors from five Cleveland area health care systems serve two-month rotating shifts on a pediatric palliative care team organized by the Hospice of the Western Reserve. Members have varied backgrounds, from critical care to bioethics. Each takes a two-month stint as director of the team, which serves children throughout the Cleveland area.

"They each bring their expertise and patient populations to the team," explains Sarah Friebert, MD, one of the physicians. "The team benefits from having different perspectives in pediatric end-of-life care."

The hospice set up the team using its good relations with all area hospitals. "We've worked very hard to build relationships with competing institutions and not align ourselves with one institution or another," says Mary Kay Tyler, pediatric team leader. The team's presence at each organization has raised the profile of pediatric palliative care and increased referrals to the team and to hospice.

The impetus was a growing sense in the Cleveland area pediatric medical community that an underserved population of sick children needed palliative and hospice care tailored to their needs. For patients, the palliative care team is an additional resource to their primary care doctor. "We're really having the benefit of everyone increasing their knowledge base, but



the families don't feel like they're being turned over to a doctor they don't know," explains Tyler. "Families have the best of both worlds."

The hospice defines pediatric palliative care broadly, allowing care at an early stage in a life-threatening illness and at any number of locations from acute care hospital to long-term care facility to home.

The hospice also created a perinatal program for parents who know they will lose a child before or soon after birth. It started after several women sought help from hospice when they found out during pregnancy they would lose their babies and didn't know how to handle it. "These are some of the most rewarding cases for the team to work with because you have the luxury of time and can really sit down and talk to the family about what they want, get a birth plan together, and prepare siblings for potential outcomes," says Tyler.

The hospice also provides bereavement care in school environments to children dealing with the loss of a classmate.

The three part-time social workers on the team have learned that palliative care for children is different from caring for adults with serious illness. Children don't always talk directly about their feelings. Counselors may spend weeks in play therapy getting to know a child before addressing the illness and a child's feelings, says social worker Michelle Miller. They also work with parents and siblings to teach how to cope with something that seems unfair and unnatural, the death of a child. "Some parents never get there," says Miller. "You respect that and just gently guide them."

That guidance could come from any member of the palliative care team. The team uses the term "transdisciplinary" as opposed to multidisciplinary, which would refer to a group of individuals who each bring a separate expertise, explains Dr. Friebert. "There's a fluidity among members of the team to fill in the cracks to make a seamless trajectory of care," she says. "Everybody just does what needs to be done for the care of that patient."



INNOVATION HIGHLIGHTS

STRONG PHYSICIAN SUPPORT AND PARTICIPATION FROM ALL HOSPITALS WITH PEDIATRIC SERVICES IN HIGHLY COMPETITIVE AREA

ONGOING CONTACT WITH PATIENTS AND FAMILIES AFTER CHILDREN MOVE OUT OF HOSPICE

COMMITMENT TO CONTINUITY WITH ESTABLISHED CAREGIVERS