

PEDIATRIC ADVANCED CARE TEAM  
DANA FARBER CANCER INSTITUTE

*Boston, Massachusetts*

“E<sup>n</sup>d-of-life care for a child presents special challenges,” says Joanne Wolfe, M.D., medical director of the Pediatric Advanced Care Team (PACT) at Boston’s Dana Farber Cancer Institute (DFCI). “Even in a tertiary care hospital, childhood death is rare, and for most children who are ill, the primary goal of care focuses on cure. Caregivers may find it difficult to recognize when it is appropriate to transition into palliative care. Physicians and other caregivers may lack experience in addressing sensitive issues with the child and the family. They’re reluctant to ‘give up’ on the child. These barriers can deprive patients and families of comfortable and meaningful times at life’s precious end.”

That’s why, in 1997, Wolfe helped establish PACT’s multidisciplinary team, with members from Dana Farber and Children’s Hospital of Boston.

PACT has no dedicated beds, and it’s not a freestanding unit. Instead, it operates as a consultation service. PACT’s approach to consultation is pro-active: Members of the PACT team routinely poll nurses regarding active patients, and a senior PACT nurse participates in morning rounds. When a patient seems appropriate for a PACT consult, a team member approaches the primary caregivers, asking the question, “Would you be surprised if this patient died within the next year?” In many cases, this question jolts caregivers from denial, and helps initiate palliative care earlier in the course of the child’s illness.



The approach is working. To date, PACT has been involved in the care of more than 100 children — 40 in the last year, indicating a marked increase. Most consults involve children with cancer, but specialists from other services have called, too, included those caring for patients with neurological disorders, cystic fibrosis and gastrointestinal disorders. Among the PACT innovations most appreciated by physicians and caregivers is a medication worksheet, developed in collaboration with a pediatric pharmacist at DFCI, for patients receiving palliative care at home. Implemented in 1999, the worksheet helps caregivers anticipate potential problems that could cause acute suffering while the patient is at home.

“PACT has changed the culture of dying among the oncology population and has created a forum through which end-of-life care issues can be anticipated and discussed openly,” says Rev. Mary Robinson, chaplaincy director of Children’s Hospital.

PACT also offers bereavement support, both for families and for caregivers. During the 18 months following

the death of a child, families receive letters and resource materials at designated intervals. An “opt-out” postcard is enclosed with the first mailing. PACT members also help organize a semi-annual memorial service for children who have died of cancer during the preceding five years. The service is well attended, offering a healing and connecting experience for families and caregivers.

In addition, PACT organizes Caregiver Bereavement Rounds, a bi-weekly conference to review end-of-life care, to report on the family’s adjustment following the child’s death, and to provide a venue for grieving over the loss of a patient.

PACT is committed to educating others, too. “We believe it is a privilege to share life’s most heartfelt moments, and to continue to learn and teach others about the care of these children,” says Wolfe, who welcomes inquiries about the program. “We are committed to promoting this model of care on a national level.”



INNOVATION HIGHLIGHTS

EXTENDING PALLIATIVE CARE  
HOSPITAL-WIDE

MEDICATION WORKSHEET FOR  
PEDIATRIC PALLIATIVE CARE

CONSULTATIVE MODEL