

Why Your Hospital Needs a Pediatric Palliative Care Program

By Shawna Bryant
Communications Specialist
Valley Children's Healthcare



Children aren't supposed to die. When a child is diagnosed with a life-threatening illness, healthcare professionals come alongside the family to work for a cure. But sadly, some illnesses cannot be cured. In times like these, pediatric palliative care offers hurting families support and essential services.

Our society does not want to talk about death and dying, and chooses instead to focus on working toward a cure. Physicians often view palliative care as the place to turn only after they've given up – and the best doctors refuse to give up. But when physicians resist calling

in the “death squad,” they may inadvertently rob a family of hope.

For the nurses and case managers involved in palliative care at Valley Children's Healthcare, palliative care is not about dying. It's about how to live with a difficult set of circumstances. Families wrestling with fresh knowledge of a terminal illness need someone they trust to be honest with them and make them aware of their choices. The pediatric palliative care providers at Valley Children's have been specially trained to work with families from the moment they learn of a life-threatening diagnosis.

Pediatric palliative care came to Valley Children's in 2004. Modeled after hospice, the end-of-life program utilizes an interdisciplinary team approach and addresses the social, cultural, spiritual and physical needs of dying children and their families. Unfortunately, this vital program is rare among pediatric hospitals. Physicians who embrace palliative care – rather than see it as an impediment to planning for optimal care and support – will not only provide the best level of care, they will also

take better care of themselves.

Why plan a pediatric palliative care conference?

To better prepare professionals for the challenges faced when caring for a dying child, Valley Children's Healthcare presented the 2015 Pediatric Palliative Care Conference. Held last month at Valley Children's Hospital, the conference gave healthcare and behavioral health providers an opportunity to increase their knowledge related to the provision of quality end-of-life and grief care.

Conference highlights included:

- Strategies to improve communication with families when discussing “bad news”
- Complexities of symptom management for end-of-life pediatric patients
- Ethical considerations that accompany end-of-life care
- Role of hospice in supporting the child and family
- Reasons and methods to develop and maintain a support network

Featured speakers and faculty

presented evidenced-based practice that is changing perceptions of the “death squad.” One of the conference presenters, Stefan J. Friedrichsdorf, MD, FAAP, serves as medical director of the department of pain medicine, palliative care and integrative medicine at Children’s Hospitals and Clinics of Minnesota. He cited a study showing that – rather than invite death – an early palliative intervention (even from the point of diagnosis) not only results in appropriate and beneficial treatments and increased quality of life for the dying child, but may actually lead to prolonged life.

Let’s work toward a cure, let’s pray for a miracle and let’s plan for what happens “if.”

Conference attendees heard case studies from Dr. Friedrichsdorf’s practice that demonstrated a child does not have to continue on disease-directed therapy in order to preserve hope, especially when the therapy significantly impacts the child’s quality of life. Pediatric palliative care empowers families to state what matters most, to make informed choices, and to feel at peace about those choices. Palliative care providers encourage children who know their prognosis to talk about their goals and what they would like to accomplish in their lives. They are given opportunities to express their wishes at the end. Will their goals be easier to meet with or without continuing treatment? Would they prefer going home or staying in the

hospital? Would they rather feel sleepy or feel pain?

Pediatric palliative care gives parents and children peace of mind because they learn what to expect. As advocates for deeper understanding of end-of-life issues, palliative care providers address sensitive issues such as:

- considering the benefit versus the burden of continuing treatments,
- discerning whether the family puts more weight on length of life or quality of life, and
- determining what quality of life means to them.

Here’s what you said. Here’s what I heard.

Dianne Gray, president of the Elisabeth Kubler-Ross Foundation and board member of International Children’s Palliative Care Network and the American Academy of Pediatrics Section of Hospice and Palliative Medicine, also spoke at the conference. Attendees gained insight from hearing about Gray’s 10-year pediatric hospice/palliative care experience with her son, Austin, who died in 2005 as a result of a neurodegenerative disorder.

Gray believes all communication problems stem from the fact that we don’t listen to understand. We listen only to reply. She stressed the importance of communication from a family perspective, and

shared conversation starters on end-of-life issues, recommending TheConversationProject.org as an excellent resource.

Faculty at the day-long conference also included medical staff from Valley Children’s, social workers, hospice professionals and community members who experienced the loss of a child. Attendees received continuing education credits and gained a new perspective about pediatric palliative care.

To learn more about the pediatric palliative care program at Valley Children’s, contact our social services department at (559) 353-5270.

Shawna Bryant is a communications specialist for Valley Children’s Healthcare, a network of pediatric care providers and medical facilities serving a 45,000 square-mile region in Central California. A nonprofit, pediatric regional medical center on a 50-acre campus near Fresno, Valley Children’s Hospital is one of the largest hospitals of its type in the nation. The 356-bed facility has a medical staff of more than 550 physicians, offers more than 40 pediatric specialties, and consistently ranks at the top of its peer group for quality patient outcomes and patient satisfaction. Valley Children’s has received repeated designations for nursing care excellence from the Magnet Recognition Program®.

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