

Palliative Care Program journeys with families through illness

TRANSFORMATION OF HOPE

Two pressed yellow flowers are positioned on the left side of the page. The larger flower is at the top, and a smaller one is below it. They are pressed onto the aged, textured paper background.

Miracles happen daily at Dell Children's, where the broken are mended and the ill are healed.

But many children are born or become ill with diseases or conditions that cannot be mended or cured. Some will have shortened lives. Others may survive injuries, but have profound disabilities. Daily life for these children is often very challenging. Parents can feel isolated, vulnerable and overwhelmed as they face decisions about treatment options and, for some, end-of-life care. They enter the medical world without a roadmap, where the language and environment are unfamiliar. As they watch their children suffer, their hearts can become heavy with anxiety, fear and sadness.

"The Palliative Care Program at Dell Children's addresses suffering in its many forms and helps patients and families create a vision of hope," says Sarah Legett, M.D., medical director of the Palliative Care Program. "The foundation of palliative care is a trusting, ongoing relationship with the child and family, allowing us to journey together through illness, no matter what the outcome."

The program partners with families, pediatricians and subspecialists to bring a holistic, family centered and interdisciplinary approach to the circle of care. It addresses the needs of the whole child—emotional, psychological, spiritual and physical—and asserts that the voice, values and concerns of the child and family are integral to quality care.

The program's services address various individual needs of these special children and families. For some children, particularly those with cancer, care includes pain management. For other children requiring multiple services and specialists, the care team coordinates services and facilitates communication among healthcare providers. Parents of chronically and critically ill children face difficult decisions along the way, including the use of artificial feeding, life support or resuscitation. The team helps the family explore what is best for their child, weighing burdens and benefits of treatment options offered by the specialists. The program's goal for all children is to optimize continuity of care across settings, whether care is provided as an inpatient, through clinics or in the patient's home.

"The Palliative Care Program has been an amazing addition to our care at Dell Children's," says Sharon Lockhart, M.D., pediatric hematologist/oncologist. "The death of a child is one of the most difficult things a family ever faces in its lifetime. Whenever death becomes inevitable, it's critical to have a process whereby the family can cope with death, integrate it into their lives and make good decisions for both the child and family in those final, months, weeks and days."

Jeffrey Kane, M.D. is a pediatric neurologist and agrees that the Palliative Care Program has made a world of difference for Dell Children's patients. "The team has prevented a tremendous amount of unnecessary suffering, both physical and emotional, for patients and their families."

For more information about the Palliative Care Program, contact the office at (512) 324-0197.

My daughter **MAYA**

During nocturnal ramblings in the last three days of her life, my daughter, Maya, shared many beautiful childhood memories. I'm glad she did because it made me realize that she had led a good life. She died on June 27, 2006, at age 13 from acute lymphoblastic leukemia (ALL). Maya passed away in our bed, surrounded by loved ones, including her oncologist, Sharon Lockhart, and her palliative care physician, Sarah Legett, who were both there for her to the very end.

Maya taught us so much about how to live life as she led us through her difficult journey. During her treatments, Maya continued to live life fully and with grace, and she set a profound example of maturing strength, compassion and understanding. Maya's oncology team at Children's did everything possible, but Maya could not be saved. In the end, massive chemotherapy treatments did not eliminate her cancer. We had to prepare for her death. It was a heartbreaking, painful experience.

The Palliative Care team helped Maya realize she could make decisions about her care and helped her plan the remaining days of her life. Maya chose to stop treatments and come home. She chose to sleep in her own bed and to enjoy home-cooked meals. She got to visit with friends, eat chicken nuggets and swim. We continued to take walks and visit the Zilker Botanical Gardens. Thanks to the Make-A-Wish Foundation, Maya fulfilled her dream of swimming with dolphins at Sea World in San Diego.

Even though we knew she wouldn't survive, those final two months at home were the best since her diagnosis. Maya had moments of sadness and tears, but not once did I hear her ask, "Why me?" She never stopped giving of herself. When she realized she would lose her hair due to chemotherapy, she donated her hair to Locks of Love. She drew strength and comfort from creating art and insisted that her artwork be sold by CureSearch in support of childhood cancer research.

I try to live each day fully, the way Maya showed us. I've joined other parents and the Dell Children's medical staff to participate in an educational curriculum, The Initiative for Pediatric Palliative Care (IPPC). Because it is so difficult to watch children die and to watch families suffer, IPPC educates staff about how best to care for children and families like mine, as well as how to take care of themselves while they do so.

Chris Hubner

My son **NATHAN**



My husband, Diwakar, and I welcomed our first child into this world on July 23, 2003. Nathan was happy, healthy and the joy of our lives, but by 18 months old, he still could not walk. That's when our son began fading in front of our eyes. By age two, he became weak and thin. By 2 1/2, he stopped eating and talking, and could no longer sit or hold his head up. His body became stiff. Nathan's disease—metachromatic leukodystrophy—is difficult to diagnose and took many months and countless doctor visits until we learned this rare genetic disease was destroying his neurological system. There is no treatment and we were told Nathan wouldn't live past the age of five. We were in shock.

Most doctors didn't have answers about his care. In our society, it's hard to talk about death. We were alone with a fragile and terminally ill child. It's frightening when you don't know when or how your child will die. Today Nathan is six and cannot move voluntarily. He cannot suck and his swallowing is partially impaired. His brain does not process information. He is very calm and comfortable. On occasion, he will smile. I would give up anything to see my son smile again.

The Children's Palliative Care team came into our lives in July 2006, for which we are forever grateful. They did not tell us everything would be okay, and we appreciated their honesty. The team became our support system and helped us create Nathan's care plan. We realized it's not the length of life that matters, but the quality of life. We knew it was up to us to make Nathan feel comfortable and loved. What would we do if he had seizures or stopped breathing or swallowing? What if he developed pneumonia? How far do we go to prolong Nathan's life? Our goal is to take care of our son, and the Palliative Care team is with us on this journey. They coordinate his medical care and appointments with other doctors and specialists. They are at our side in the emergency room and go above and beyond the requirements to make sure he is properly cared for.

Human tragedy surrounds us all the time and happens more than I was aware. Being Nathan's mother has taught me about life.

Having a terminally ill child doesn't make us better human beings; it makes us more human, more real. It's taught me to appreciate the small things. I've learned that I can't control what happens, so I enjoy one day at a time. And the Palliative Care team has taught me all about the meaning of kindness.

Diana Kuai

