AWARD WINNER

# CHILDREN'S PROGRAM OF SAN DIEGO HOSPICE AND CHILDREN'S HOSPITAL AND HEALTH CENTER

*San Diego, California*

Just say, "yes." That's the informal motto that guides decisions made in this innovative, pediatric end-of-life program. A remarkable collaboration between San Diego Hospice (SDH) and Children's Hospital and Health Center of San Diego, this program brings the palliative medicine strength of a nationally-recognized state-of-the-art hospice to the pediatric expertise of a renowned children's hospital.

Caring for dying children has long been part of the mission of San Diego Hospice, which opened in 1977. But in 1998, recognizing that there was both a need and an opportunity to broaden end-of-life care options for children and families, the hospice and hospital joined together to create a formalized collaborative program sharing resources and clinical expertise.

"Connecting the two organizations was logical. Each offered excellent care, but the hospice side was missing a formal pediatric component; and the hospital was missing the end-of-life piece," says David Sine, M.D. Board-certified as a pediatrician, Sine serves both as an admitting physician and as medical director of the Children's Hospice Program — a dual role that provides a key link in the collaboration.

The two organizations planted the seeds for their eventual collaboration when Sine and Liz Sumner, director of the Children's Program, became members of the hospital's bio-ethics committee. "We saw that many cases under consideration involved withdrawal of nutrition, hydration and ventilation — some of the most difficult challenges in pediatrics," says Sumner. "It became clear that the SDH Children's Program, having dealt with these types of issues, had something positive to offer. We could often contribute a family-centered palliative approach or provide care in the home or hospice inpatient care center.

Today, the program is known as a pioneer of a model to deliver the highest standards of hospice care for infants, children, and adolescents with life-threatening illnesses. The program also addresses the needs of children who are experiencing the serious illness of a family member or friend. In addition, it supports families throughout a child's illness and following death (or graduation) works to create a seamless continuum of support. "We prefer to call it a children's program, rather than a pediatric program, because it encompasses a lot of people impacted by the death of a child," says Sumner. For those who graduate, the Reach Program for medically-fragile children, offers nurse practitioners who make home visits.

Collaboration is a trademark of the program. The hospice provides management oversight; clinical coordination; the primary team of nurse, social worker, home health aide; as well as pharmacy and inpatient and bereavement services. The hospital provides physician consultation and home visits, home infusion therapy, a childlife specialist, psychiatry, and lab and educational services. Both organizations contribute a broad range of complementary therapies. Parts of the program are housed at San Diego Hospice, while others are at the hospital, forming a continuum of care aimed at covering the full range of needs and ensuring optimal quality of living and dying. And recently, the hospice team began wearing hospital ID badges, demonstrating its growing integration into the hospital's culture.

"Our collaboration is working well, because everyone goes outside of the typical hospital and hospice boxes," says Sine. "It's not a we/they situation. Our strength comes from the combined wealth of knowledge and dedication of two great organizations."

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Innovation and adaptation to new circumstances have been necessities as well as strategies. Three years ago, for example, the hospice team met a family whose young son was brain dead, after drowning in a swimming pool. He was on a ventilator in the hospital's PICU. Members of the hospice and hospital team met with the family to discuss options for the family, including taking the child home or to the hospice inpatient care center to be extubated. That first discussion led to creation of the Compassionate Extubation Program, which has since cared for more than 20 other patients.

Similarly, an Early Intervention Program got its start in response to another family's special needs. Today, the program reaches out to parents who have been informed that their unborn child has a life-limiting or threatening illness, assisting the parents in developing a birthing plan, choreographing their experience to make it personalized, advocating for their needs, attending at the delivery if the family so wishes, and offering a highly-specialized bereavement program.

"When an unusual situation presents itself, we try to look at it through the overarching view of our mission — rather than making it fit into already existing procedures and structures," says Sumner. "We'll say, will it provide comfort? Is it consistent with the goals of the child and family? Will it preserve quality of life and offer time for the family to cherish together?' Then we say yes, and build our services around the individual circumstances."

Not surprisingly, the program has made many friends. "People — meaning families and doctors — are getting more comfortable about sending children to us," says Sine. "The most frequent comments we hear from families are, 'Thanks for being honest with us,' and 'Thanks for making my child comfortable.' Being able to offer this kind of care and support — and the hope that it engenders, has changed my life as a caregiver."

The program is having an impact on others, too, because both hospice and hospital are eager to share their experiences. To that end, the program openly offers consultation, sharing of clinical resources, and information to other organizations trying to serve children with life threatening illnesses. It maintains a strong affiliation with San Diego's three nursing schools, provides training of pediatric residents, and conducts a mini-clerkship for medical students from the University of California–San Diego.

"We know that most adult hospice programs feel woefully inadequate to take care of kids, but many want to do better" says Sumner. "The types of diseases and circumstances that lead to death for a child are very different, and often unpredictable. And most hospitals — especially those that specialize in pediatrics — really don't want to focus on the dying process and the death of children. We think we've found a model that works, and we see our emerging success as a wonderful opportunity to help make it possible in other communities." •

INNOVATION HIGHLIGHTS

**COMPASSIONATE EXTUBATION PROGRAM**

**EARLY INTERVENTION PROGRAM FOR PARENTS WITH PRENATAL DIAGNOSIS THAT IS THREATENING TO THEIR UNBORN BABY**

**USE OF PEDIATRIC HOSPICE STANDARD ORDERS AND PROGRAM-SPECIFIC GUIDELINES**