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July 17, 2006 ■ Volume 3 ■ Number 16



Above and About the Cover: After Mercy Medical Center Merced (MMCM) merged with Merced Community Medical Center, bringing the staffs together was not unlike combining two different families when the parents get remarried. Fortunately, the merger paid off, especially for the endoscopy and infusion unit at MMCM's Dominican Campus. Seamless teamwork among techs and nurses like Don Miller, RN, (left) and Rhonda Hernandez, RN, is the reason for the unit's high patient satisfaction scores. (Photos courtesy Mercy Medical Center Merced)



Cover Story

And Then There Was One | 12

Even after the consolidation of two, large outpatient units into one facility, nurses of the endoscopy and infusion unit at Mercy Medical Center Merced's Dominican Campus never miss a beat when it comes to providing quality care. Just ask their patients. The department is among the highest in patient satisfaction scores in the Catholic Healthcare West system.

Features

CE: Delegation Defined | 15

Sally Ann Corbo, EdS, RN, CNAA, tackles a big issue in nursing — how to work with and delegate jobs to unlicensed assistive personnel and ancillary workers in your healthcare facility. Read this for-credit article — worth 1 contact hour — and learn exactly what delegation means, the “five rights” of delegation, factors to consider in deciding to delegate, barriers to delegation and the role of the delegator.

ADVANCE Extra! Pediatric/Neonatal Nursing | 19

The Pathways KIDS program, treating pediatric GERD, lead poisoning, pediatric narrow complex tachycardia and more are topics covered in this installment of *ADVANCE Extra!*, our magazine within a magazine.

Education Series, Part 4: Refresher Courses | 32

An estimated 16.8 percent of the nation's RNs are not working in nursing. Many more are still in the profession, but away from the bedside. Refresher courses are designed to help RNs return to clinical practice with confidence in their ability to function competently in a patient care setting.

Coming July 31

Do you know everything the Greater Sacramento region has to offer? To find out, don't miss the next regional *ADVANCE-Extra!*, highlighting what it's like to live and work there, what schools are available for continuing education and who's hiring.

**Merion Publications Inc., ADVANCE for Nurses,
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advance Extra!

Pediatric/Neonatal Nursing

A Life Abbreviated

Pathways KIDS goes beyond hospice to offer comprehensive palliative care to children with life-threatening illnesses and their families BY SHELBY EVANS

IN THE FACE OF A PROBABLE terminal prognosis, a child's life becomes abbreviated — condensed and punctuated with extreme highs and lows. For the parents, questions concerning their child's illness and care run from technical to emotional, medical to spiritual.

To aid in the search for answers, Pathways KIDS, initiated in the San Francisco area in 2003, surpasses traditional hospice with a palliative care program tailored to the unique needs and experiences of children coping with a life-threatening illness.

Karen Herzog, who sought the program's services for her daughter, Sophia, knows the parental turmoil firsthand. "There's such a huge need for palliative care for kids; the care isn't adequate for children and families," she emphasized. When confronted with such an unimaginable reality, "most people don't understand; even pediatricians may not know how to deal with it, especially if it's a rare disease."

A Broader Vision

In its 30-year history in the Bay area, Pathways Home Health & Hospice in Sunnyvale has intermittently provided hospice services to children. In recent years, an emerging vision of palliative services as part of the child's care continuum, rather than a discrete end-of-life service, inspired the inception of Pathways KIDS. Pathways hired pediatric specialists to work alongside the experienced palliative care team in a family-centered and developmentally appropriate approach. It identified gaps in care for children and



MAKING MEMORIES: Karen Herzog shares a special moment with daughter Sophia.

families facing life-threatening illness, and developed a program that meets these needs. Today, the 11-member team includes nurses, social workers, spiritual care counselors and a pharmacist, as well as volunteers.

Since its creation, Pathways KIDS has served 93 children and their families, largely through referrals from University of California San Francisco Children's Hospital and Lucile Packard Children's Hospital (LPCH) at Stanford in Palo Alto. The program provides care for children in San Francisco, San Mateo and Santa Clara counties who are not expected to live to adulthood.

Cancer is the most common condition among the program's patients, according to Joyce Shefren, RN, CHPN, patient care manager for Pathways KIDS, along with birth anomalies, including a rising number of trisomies. Typically when the team gets involved, "these children are at a critical phase and ▶

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Welcome to *ADVANCE Extra!*, a supplement that appears periodically throughout the year. This issue's *ADVANCE Extra!* spotlights pediatric/neonatal nursing and includes current information about these specialties, as well as career opportunities at local healthcare facilities.

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may be expected to survive less than a year," Shefren said.

The World of a Child

The distinctions between adult and child palliative care are developmental, social and clinical. "There's so much that happens between birth and age 18," said Sharon Mills, MSN, CPNP, noting developmental stages are compressed during childhood.

"One of the issues with kids is that they're growing at the same time they're dying," Herzog pointed out. "I mean, Sophia grew." In the program's care, her child developed from 20 months to age 4.

"The difference of just a couple of years means a different approach to treating the child, communicating with him and helping him live in the midst of a life-threatening problem," Mills emphasized. "You can't explain the ins and outs of cancer to a 3-year-old who lacks the verbal and cognitive skills to describe or understand his fears. You do make sure mom can stay in the room and keep his world as normal as possible."

On the other hand, teenagers are trying to be autonomous, but are suddenly thrust back into dependence. "There's a lot of anger that goes along with that," Mills said. "Body image is paramount at that age and sometimes treatments disrupt that. Chemotherapy makes their hair fall out or makes them gain weight; surgeries might be disfiguring. They're being cut off from their peers at a point when their world revolves around them."

At Pathways KIDS, care is an all-encompassing concept — from medical and spiritual support to bereavement. Pain management is not the only issue, and end-of-life comfort is not the only priority.

Full-Spectrum Care

At Pathways KIDS, care is an all-encompassing concept — from medical and spiritual support to bereavement. Pain management is not the only issue, and end-of-life comfort is not the only priority. In terms of medication, "nausea and vomiting are big concerns. Anxiety and sleep problems are other issues," Mills stressed, noting that children facing a life-threatening illness often are afraid of going to sleep. For kids who want to continue attending school, meds that boost energy levels are important.

Physical therapy often figures into treatment plans as well, Mills continued. "Sometimes our kids are suffering the effects of treatment, and physical therapy can help them feel better and regain some mobility."

The innovative program offers holistic and alternative therapies as well, Shefren added. "We have a new integrative therapy team providing Reiki, music, art therapy — a lot of different things to work with siblings, friends and patients." There is 24-hour on-call support from a nurse or social worker.

Shefren emphasized the program's services are ongoing beyond a child's death. "We continue to see the family for 13 months or so after the death," she explained, citing the criteria for hospice bereavement care. Staff con-



SHARING SOPHIA'S STORY: Photography was contributed by Karen Schreiber, MSN, FNP, a documentary photographer in Palo Alto, who photographed Sophia Herzog-Sachs with her family and care team, to document Sophia's experience and share her legacy. Through Sophia's family, Schreiber was introduced to Pathways Home Health & Hospice, where she now works as a hospice nurse.

tinue to work with the siblings of the child. This coming fall, she added, "We will begin a children's grief program that provides individual and group support."

A Conceptual Barrier

"In the pediatric world, we try not to dwell on the idea of hospice," Shefren said. "Parents don't want to think about their child being a hospice patient." The Pathways team has found this conception can be a barrier for both professionals and parents.

"There's such a fear in physicians and in the hospital of bringing up bad news that we often don't get involved until pretty late in the course of the child's illness," Mills said, adding that she wishes those involved in the child's hospital care "would recognize we can enhance care throughout the child's course of treatment." If the outcome is positive, she noted, the child would be discharged. But if the outlook turns bleak, "then we're already there; the family knows us and we can continue to support them through the end of the child's life."

Herzog said the program "opened up a whole new door for us in end-of-life care we had not experienced before and were very frightened of." But, she discovered, "it doesn't mean giving up, just getting more support."

Sophia's Story

In March 2002, 10-month-old Sophia Herzog-Sachs was diagnosed with Niemann-Pick disease Type A, a rare genetic disease affecting lipid metabolism that ultimately results in organ system failure. There are no effective treatment protocols for the disease; there is no cure.

At 20 months of age, having been hospitalized for several apneas, Sophia was referred to Pathways by LPCH with the expectation she might survive a week.

But Sophia rallied. Her parents, Richard and Karen, developed a holistic approach that embraced Sophia's comfort needs and possible death and the

hopeful pursuit of treatment and survival. "When Pathways came in, we hadn't yet figured out the home care; she had an NG tube and had lost a lot of her mobility; she was on a steep decline," Herzog remembered.

The assistance was medical, emotional and spiritual, she added. "I got over my fear of Sophia dying. I had been afraid to even touch her. I was so frightened she would die in my arms."

The Course of Events

Often with a terminal prognosis, the treatment choices are slim. Though traditional hospice services pave a path toward an expected end, they may neglect to support a parent's instinctive need to hope and work to find treatments.

Despite the bleak prognosis, "we were hoping we could change the course of Sophia's disease," Herzog explained. "We had been pretty much focused on whatever treatments we could come up with." When Pathways became involved, she began to toggle between pursuing treatments and preparing for end of life. "You need to be prepared that your child's life can go either way," she said.

The Pathways KIDS program "allows whatever course is going to develop," Herzog continued, explaining she was never handed a rigid formula for how to care for Sophia. "There is an openness to what works best for each particular child and his or her family." Her treatment model for Sophia was holistic and fit well with the integrative therapies program. "We didn't have to change who we were."

Sophia battled her illness for 2 1/2 years beyond her original prognosis, surviving apnea, seizures, hydrocephalus and numerous other life-threatening complications. She ultimately succumbed to hepatic renal failure on July 25, 2005. Her family continues to receive support from Pathways KIDS "way beyond what I had ever imagined," Herzog said.

An Impossible Choice

The division between end-of-life hospice care and the pursuit of treatment is systemic. Federal, state and private insurance hospice eligibility requirements generally state a patient must have a life expectancy of less than 6 months and must discontinue curative treatment. But when the patient is a child, families need to maintain hope and pursue treatment, even while receiving palliative care. To a parent, choosing a single course is untenable.

"There isn't adequate reimbursement in California and other places. They're making parents make this choice," said Shefren, who sat with Herzog as she told Sophia's story to *ADVANCE*. "We fund-raise in the community so we can support these families. That was a choice Pathways made when we started this program."

"No one expected Sophia to rally the way she did; it's just unbelievable," Herzog said. "Were we supposed to just give up? Pathways KIDS eliminated our having to make that choice."

The Medicaid and Medicare hospice eligibility requirements are federally mandated, but states can waive the requirements under Medicaid through their department of health. Currently, Mills noted, the Children's Hospice and Palliative Care Coalition is working with the California Department of Health Services to eliminate the 6-month prognosis and treatment barriers when the patient is a child, permitting these families to benefit from both courses of care.

"It's impossible for these families to give up and say 'No, we're not going to try anything else,'" she said. "They're going to exhaust all

possibilities as long as it's not detrimental to their child."

If the state waiver is signed and implemented, Mills added, "we'll have more ammunition to go to the doctors and say 'now we can be involved sooner' without taking away from the care you want to provide.

"That's going to be a huge step forward." ■

Shelby Evans is associate editor at ADVANCE.



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