



Pediatric Clips

NURSING

*Pediatric home care —
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Pediatric Nursing Clips by Pediatric Advanced Practice Nurses at Dayton Children's provides quick reviews of common pediatric conditions.

The Children's Medical Center of Dayton is the region's pediatric referral center for a 20-county area. As the only facility in the region with a full-time commitment to pediatrics, Dayton Children's offers a wide range of services in general pediatrics as well as in 35 subspecialty areas for infants, children and teens. We welcome your inquiries about services available — call 937-641-3666 or e-mail marketing@childrensdayton.org.

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CASE STUDY

Katie was a 37-week-old newborn with hydranencephaly, which is the lack of the cerebral hemispheres. She was in no acute distress and was able to feed orally. Her parents met with the neonatologist and were given a

neurosurgery consult. The neurosurgeon felt that surgery would be life-threatening for Katie. The parents made the decision not to treat Katie and to take care of her at home. They wanted to keep her at home and allow her to die

surrounded by family. The parents signed a do not resuscitate (DNR) form and she was entered into the Care and Comfort program through Children's Home Care of Dayton.

CASE DISCUSSION

At one week of age Katie went home with her parents and 5-year-old sister, Kara. The family had strong support from the maternal grandmother, paternal great-grandmother and numerous other family and friends. The Care and Comfort program arranged for a family support specialist to provide bereavement support to the parents, sibling and extended family. Both parents were concerned about the 5-year-old and how to explain Katie's illness and short life span. The family support specialist met with Kara and her mother to play board games and provided books designed to assist children in dealing with death and dying. Katie and her family received weekly nursing visits when she first went home and planned to increase the frequency of visits as her symptoms progressed. The family was in close contact with their pediatrician and was comfortable calling him with any concerns. Katie's head circumference increased by 1cm weekly, which caused her to have irritability, tremors and decreased oral intake. She was started on Lorazepam to make her more comfortable. As Katie's head circumference increased, nursing provided the family with gel pads to prevent skin

breakdown. The increased intracranial pressure continued to compound her symptoms and Tegretol was added to her medications to manage seizure activity.

A care conference was scheduled with neurology and the family to discuss her treatment. Katie passed away quietly at 4 months of age at home with her parents. Her primary home care nurse went to the home to pronounce her death, called the pediatrician and the coroner's office. She assisted the family in bathing and dressing Katie and family members were given an opportunity to hold her. When the family was ready the funeral home was called. The family support specialist continues to see the family for bereavement support.

CARE AND COMFORT

Although dying is a part of life, a child's death, in a real sense, is unnatural and has a devastating and enduring impact¹. When children experience life-threatening and incurable progressive conditions, the need for palliative care is important. Children's Home Care of Dayton developed the Care and Comfort program to help meet the needs of families whose children

have a life-threatening illness. The goal of the program is to provide family-centered care that respects the dignity and uniqueness of every child and family. The program's comprehensive services allow parents to care for their seriously ill child in the home. Services provided are:

- Pediatric nursing visits with on-call staff available
- Infusion therapy
- Pain and symptom management
- In-home blood transfusion
- Intensive family support
- Interdisciplinary team case management
- Coordination with community resources
- Family support specialist to provide individual and family support
- Bereavement support

A child is admitted to the program by a referral from a physician who will manage the patient's care and the patient and family must want to participate in the program. The patient does not have to have a DNR to be in the program unless the patient or family wants the child to die at

Continued from the front.

home. Without a DNR, the family would need to call 911 if the patient deteriorated in the home. When preparing for a child to be admitted to the program, nursing care considerations include: assessment for appropriateness for home care, the family's understanding of the disease process, plans for symptom management and bereavement support. The family must have an understanding of what caring for the child will involve including time demands, physical demands, work responsibilities, siblings needs and the amount of support available from family members and friends. Equipment such as a hospital bed, wheelchair, bedside commode

or an over bed table may make care at home easier. In addition, culture plays a role in every family; it defines how the family views illness, death, and bereavement practices. When these beliefs are honored, it provides comfort and peace to the family.

Physicians, nurses and other health care workers usually play an important role in the lives of children facing life-threatening illnesses and their families. Each family is unique and our goal is to help the patient be comfortable and enjoy life to the best of their ability. Parents should feel that they have had the support and information to make good decisions for their child and that they have been good parents.

References

1. Behrman, R. When Children Die: Improving Palliative and End-Of-Life Care For Children and Their Families. Washington, DC: The National Academies Press; 2003.

FEATURED NURSE SPECIALIST



GERRI SHEEHAN, RN, MSA, is director of clinical services for Children's Home Care of Dayton. She

has been with The Children's Medical Center for 37 years. She graduated from Good Samaritan School of Nursing, obtained her bachelor's degree from Wright State University

in 1993 and completed her master's from Central Michigan University in 1999. Gerri, along with Emmett Broxson, MD, and other members of the hematology/oncology department, developed the Care and Comfort program in 1999.

CARE AND COMFORT AT DAYTON CHILDREN'S

The staff of Dayton Children's Care and Comfort understand the needs of children with life-threatening illnesses and their families.

The goal is to provide family-centered care that recognizes the significance and distinctiveness of each child and family. The family determines the specific services provided. With a primary care physician, care team members support the family in their decisions, allowing them to care for their seriously ill child at home. For more information about the Care and Comfort program, call Gerri Sheehan at 937-641-4663.



For further information about The Children's Medical Center of Dayton or its nursing program contact the nursing recruiter at 937-641-3666 or marketing@childrensdayton.org.



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