HOSPICE OF THE WESTERN RESERVE

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OUR MISSION
Hospice of the Western Reserve provides palliative and end-of-life care, caregiver support, and bereavement services throughout Northern Ohio. In celebration of the individual worth of each life, we strive to relieve suffering, enhance comfort, promote quality of life, foster choice in end-of-life care, and support effective grieving.

THE DOCTOR IS IN
Pediatric Palliative Care Important Component for Seriously Ill Children
By Sarah Friebert, M.D.

In a perfect world, no parent would have to experience the serious illness or death of a child. But it is not a perfect world and 53,000 children die in the United States each year. For these families, as well as the families of the more than 500,000 children suffering from life-threatening conditions, a pediatric palliative care (PPC) team can help enhance the child’s quality of life, help parents make informed decisions about treatment options and help address the family’s psychological, spiritual, emotional and practical needs. Working in concert with other involved providers, a PPC team offers comprehensive, interdisciplinary, family-centered, team-based care for patients of all ages, from prenatal to young adult.

Palliative care is a growing subspecialty in pediatric medicine. The first hospital-based PPC began about 15 years ago, and can now be found in a majority of children’s hospitals. Most children referred to palliative care programs have life-threatening neurological or neurodegenerative conditions, trauma, complications of prematurity, chromosomal/genetic abnormalities, complex congenital heart disease, cancer, or metabolic diseases.

A common misconception is that there is no place for palliative care until all curative, life-prolonging options have been exhausted. In fact, rigid distinctions between curative and palliative interventions may hinder appropriate provision of palliative care, and many treatment options fall into both categories.

At or shortly after diagnosis, palliative care physicians and team members meet with the child and family to identify their goals and develop an individualized plan of care. In addition to management of pain and other distressing symptoms, the PPC team assists the family in goal-directed decision making, care coordination, management of transitions, anticipatory grief/bereavement, family coping and resiliency, and many other aspects of being or caring for a child with a life-tening condition.

The relationship between the PPC team and the family can extend for months, years, or even decades. Sometimes children even graduate from PPC. When children do die, the palliative care team follows up with families at regular intervals through mailings, individual phone and in-person counseling, group support, remembrance services, and anniversary/birthday cards.

In short, PPC is not just about death and dying. The American Academy of Pediatrics has stated that when a child is facing a serious illness, the goal should be to add life to the child’s years, not simply years to the child’s life. As the mother of one of my patients put it, “When we first heard about PPC, we thought it meant that everyone had given up on my son. We soon learned otherwise, and now we don’t know what we did before you came into our lives. Who wouldn’t want this kind of care?”

Sarah Friebert, MD, FAAP, FAAPHM, founder and medical director of Akron Children’s Hospital’s Haslinger Family Pediatric Palliative Care Center, is board certified in Pediatric Hematology/Oncology and Hospice and Palliative Medicine. She is Professor of Pediatrics at Northeast Ohio Medical University, a past recipient of the Miracle Maker Award from the Children’s Miracle Network, and the inaugural holder of an endowed chair created in her name.

Dr. Friebert also serves under contract as Hospice of the Western Reserve’s Pediatric Medical Director.

Editor’s Note: This column features perspectives from guest physicians. Submissions are welcome. Send column ideas to: lhenrichsen@hospicewr.org.
In this issue, Clinical Connections interviews Mary Kay Tyler, RN, CNP, CHPPN, Director of Pediatrics and Clinical Support Teams, about perinatal care. A certified nurse practitioner, Tyler was employed 10 years as a nurse practitioner in pediatric oncology, specializing in brain tumors prior to joining Hospice of the Western Reserve. Tyler is a certified Pediatric End-of-Life Nursing Education Consortium (ELNEC) instructor. She has presented on the local, state, and national levels on a variety of pediatric palliative care topics.

Q: What is the overriding philosophy behind the perinatal care program?
A: When prenatal testing reveals a baby may be born with a life-threatening or chronic condition, the family is faced with overwhelming uncertainty and grief. Our perinatal care team works with these families on their journey through pregnancy, birth, and death, honoring the baby as well as the baby’s family. It is a compassionate and supportive way of caring for the pregnant mother, the baby, and the entire family with dignity and love.

Q: What are the roles of the team and how does the team interface with the expectant mother’s obstetrician?
A: Our perinatal care team collaborates with the obstetrician and/or midwife to formulate a care plan. The perinatal care team helps families identify community resources and support groups while navigating the health care system and maximizing social service support.

Q: What members comprise the perinatal hospice care team?
A: The consulting pediatric medical director or team physician provides guidance to the team on pain and symptom management, ethical dilemmas and decision making. A nurse practitioner supervises the team, providing consultation and clinical care. A nursing assistant provides personal care for the baby, and the spiritual care coordinator offers support and guidance in the family’s search for meaning, connection, spiritual strength and peace. The pediatric nurse visits the baby and provides instruction to the family on ways to simplify feeding, medication and other issues. A social worker assists in choices during pregnancy and after the birth, and identifies legal and financial resources for the family. Other core members of the team include expressive therapists, who use art and music to help families express their feelings, a massotherapist who uses touch and massage to comfort the baby and a pediatric bereavement coordinator to guide parents, siblings and other family members through feelings associated with grief and loss. Trained volunteers provide supportive visits as well as respite for the family.

Q: What else does the perinatal team do for families?
A: There are many ways in which we support families. These include creating a plan to determine the family’s preferences at birth, addressing emotional needs, including those of siblings and grandparents, coordinating hospitalization and discharge of the baby, assisting in creating keepsakes and helping with final arrangements, memorial services and goodbyes, as needed.

Q: Does Hospice of the Western Reserve offer any additional services to these families?
A: Yes, the baby may stay at one of our two in-patient care centers – David Simpson Hospice House on Cleveland’s east side, or Ames Family Hospice House in Westlake. Trained volunteers offer respite care, providing the caregiver with a much-needed break or time to participate in normal family activities. We also provide on-call support 24/7 and medications and medical supplies are delivered to the family’s home.

Q: How is perinatal hospice care financed?
A: Hospice of the Western Reserve is a nonprofit organization providing services regardless of an individual’s ability to pay. Hospice and palliative care services are covered by many private health insurance plans as well as Medicare and Medicaid. We also rely on memorial gifts, grants, private donations and community support.

Q: How are referrals made?
A: A referral to our perinatal care program can be made by anyone, including a family member, friend or health care professional by calling 216.916.5520. A member of the team will return the call the same day.
CASE STUDY

**Peds Team Support Improves Quality of Life for Patient and Family**

Husam is an 18-year-old who is developmentally at a three-month-old level with cerebral palsy, seizures, and respiratory failure. Hospice of the Western Reserve’s pediatric palliative care team met Husam and his mother in June after being contacted by the hospital where he had been receiving treatment. The family emigrated to the U.S. from Iraq under refugee status in their quest to find medical support for Husam. An older brother with similar disorders had died in Iraq.

The goal of Husam’s mother was to make and keep her son comfortable so the two could return to their U.S. home. The hospital staff supported her in this decision and discussed what supports could be used at home to manage respiratory changes.

Hospice of the Western Reserve’s pediatric palliative care team worked closely with Husam’s mother to provide her with the education to care for him in their own home. Goals included weaning him off the ventilator, providing bi-pap support at night and oxygen during the day; a feeding tube was placed to support his nutritional needs. Once his symptoms were controlled, the team met with other family members involved in his support. The 24/7 on-call support system was reviewed and volunteer support was arranged to provide the family with respite to help better manage daily activities.

Since seizures were also a problem, medications to manage occurrences were placed in the home. Education and equipment were provided to help Husam’s mother safely bathe him, and twice weekly visits from a nursing assistant were arranged.

The team social worker helped Husam’s mother to apply for a waiver to permit the family to remain in the U.S. for health and humanitarian reasons, and to ensure Social Security benefits were put in place. Calls were placed to local organizations to obtain a wheelchair and car seat to allow Husam greater mobility with his family. The social worker also applied for funding for a flat screen TV for Husam’s room to be used in conjunction with devices from his school to provide greater stimulation.

The team’s support extended to the school setting. The team worked with a physical therapist to make adaptations that would allow Husam to be comfortable in his wheelchair all day, and they counseled school staff about Husam’s special needs.

Just as important as the care provided to Husam is the support the team provided to his mother. With the additional resources in place, she was able to get much-needed breaks from caring for her seriously ill child to attend to personal appointments, take occasional walks and even to gradually increase her independence by obtaining a driver’s license.

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**Go Mobile with iRefer App**

Hospice of the Western Reserve is streamlining the hospice referral process with a new mobile application for iPhone, iPad and Android users. The free app eases referrals, increases efficiency and eliminates paperwork by providing physicians and other health care professionals with the ability to electronically sign orders.

To download the app, simply search for “Hospice of the Western Reserve” in the app store and tap “Free.” Referrals submitted through the app will be received by Hospice of the Western Reserve for expedient follow up. Health care providers will also find guidelines on hospice eligibility and reimbursement. All patient information received through the referral form will be managed with HIPAA compliance.
**RESEARCH CORNER**

**Results of Research Study on Statin Use Beneficial to Hospice Patients**

By Christine Morehead

Many individuals and their families cope with significant burdens imposed by serious illness in the final months of life. How to best support their quality of life is an important care consideration for Hospice of the Western Reserve. Research can play a vital role in providing answers that will guide and shape the science of palliative care for current and future generations of patients and their families.

Although much research has been focused on keeping people healthy or restoring them to health, few clinical trials have been devoted to improving outcomes for individuals with life-defining illnesses. Hospice of the Western Reserve became a member of the Palliative Care Research Cooperative (PCRC) to address the need for more evidence-based research. Prior to becoming a partner in the study, we verified that the protocol was reviewed and approved by an accredited Institutional Research Board, and that all the procedures were in place to ensure that patients, their physicians, and families were fully informed of the pros and cons of participation and able to make informed decisions.

**Study Examines Continuation Versus Discontinuation of Statins**

One of the Cooperative’s first studies focused on analyzing the continuation versus discontinuation of statins for hospice patients. Statins are a group of drugs that help patients lower their serum cholesterol levels. By doing so, patients are less likely to develop blockages in their arteries and they might then avoid having a heart attack or a stroke. But are these drugs still helpful when a person has only a few months to live? Medicines can be expensive, ill patients often have a difficult time swallowing their pills, and medication side effects can occur. A drug intended to prevent a heart attack may not show much benefit if a person has only a few weeks or months left to live.

In this study, patients were enrolled in one of two groups: One group continued to take their statin and the other group did not. The PCRC established the goal of enrolling 360 patients nationwide within a two-year period. The study closed with a total enrollment of 380 patients.

Hospice of the Western Reserve began participating in the study in October of 2012. A total of 16 patients enrolled and participated throughout the six months. The study’s primary purpose was to determine if there is a difference in survival time between patients with advanced life-limiting illness for whom statins are discontinued and patients who are maintained on the medication.

**Study Results**

The group that stopped taking their statins did not experience an increase in heart attacks or strokes, their median time until death was actually longer, and they had a better quality of life. The clinical question of whether to continue or discontinue statins in the last year of life remains a patient-centered decision, where clinicians and patients together talk about what to do. However, our clinicians can now feel confident in recommending to our hospice patients that they can safely discontinue one of their meds if they so choose.*

Hospice of the Western Reserve will continue to participate in clinical research that can lead to genuine progress in palliative care and a better quality of life for patients at the end of life.

*Full details of the study will be available upon publication of the study.

Christine Morehead, B.A., CCRP, has been a full-time Certified Clinical Research Professional at Hospice of the Western Reserve for the past four years. For more information regarding the agency’s research initiatives, contact Christine Morehead, Clinical Research Assistant at 216.701.4448, or cmorehead@HospiceWR.org.