



Team-teaching About Palliative Care for Kids

SR. MARY MAXINE YOUNG, SND, and BETH E. WHITE, MSN, RN, CNS

Palliative care has a long history in Catholic health care. The word “palliative” is derived from Latin and means to “lessen the severity of,” “to cloak” and to “provide comfort,” thus palliative care focuses on relieving distressing symptoms and improving quality of life. Ideally, professionals learn palliative care concepts early in their career, taught by members of an interdisciplinary palliative care team. They learn about the important goal of reducing suffering caused by a life-threatening or life-limiting illness. They also learn that suffering takes many forms, and no one professional can effectively meet all of a palliative care patient’s physical, spiritual and psychological needs. It takes an interdisciplinary team of physicians, nurses, social workers and chaplains.

To help drive that concept home, we teach palliative care as a team at Mercy St. Vincent Medical Center/Mercy Children’s Hospital in Toledo, Ohio. Our teaching team may consist of a chaplain and a pediatric clinical nurse specialist, or a palliative care physician or a palliative care counselor. We want our students to hear viewpoints about providing palliative care from both pastoral care and medical perspectives, and we want to help them address an important lesson: The special requirements of children and young adults can cause any and all professionals to doubt their ability to ease suffering. Especially when they are new to palliative care, a caregiver will wonder about being of any help at all.

Those trained to support spiritual and emotional growth and development worry about saying the right words and being present at the right times. Meanwhile, medical providers expect

chaplains to understand the reasons for spiritual suffering; many simply assume that chaplains have it all together spiritually. That is certainly not true.

On the other hand, even experienced physicians and nurses worry about listening purposefully and discussing medical concerns in a compassionate way with their palliative care patients. Yet chaplains may expect that, because physicians and nurses have seen so much suffering, they are reconciled to its effects, and experience has taught them how to best work with and help their very sick patients. That is certainly not true.

This is why team-teaching about palliative care can be so important and effective. The providers of physical care and spiritual care share self-doubt in the face of suffering, but neither group realizes they aren’t the only ones. They also underestimate the strength they will draw and the relation-



Very ill children have helped us understand that we all have a purpose, no matter the length of our life.

ships they will forge with team members, patients and families. Teaching as a team, a medical and a spiritual provider can offer their own viewpoints and draw out specific questions and concerns.

Here is a typical palliative care presentation drawn from our team-teaching experiences. The names of the children involved have, of course, been changed to protect their privacy.

OUR BEST TEACHERS

Jared, Sr. Adeline, Dave and Sarah were all third-year seminary students completing a summer residency in our hospital's clinical pastoral education program. On this day, we were presenting our perspectives on pediatric palliative care and the chaplain's role within the interdisciplinary team.

Together, we have more than 12 years' experience in maternal-child and pediatric palliative care as chaplain and pediatric clinical nurse specialist. Consequently, we weren't surprised at the students' initial reactions: "I don't know how you do it!" "If I am assigned to work on the pediatric unit, I will fall apart!" "I could never work with sick kids, especially really sick kids! That takes a specialness that you have to be born with!"

RESOURCES

There are many resources available to help chaplains, children and families cope with serious illness and death. Here are a few we have found especially useful:

Empty Arms: Coping after Miscarriage, Stillbirth, and Infant Death, by Sherokee Ilse (Wintergreen Press, 2008).

When Families Grieve: A Special Guide for Parents and Caregivers (Sesame Workshop, 2010). Available online at www.sesamestreet.org.

Bobby's Books: Using Books to Help Build a Child's Coping Skills. A bibliotherapy program of Midwest Care Alliance, Columbus, Ohio. Information online at www.bobbysbooks.org.

Selected brochures from the CareNotes collection, Abbey Press, St. Meinrad, Ind.:

"Finding the Courage to Face a Serious Illness"

"Grieving: When You Lose Someone Close"

"Helping a Child to Grieve and Grow"

"Right and Wrong and Being Strong: A Kid's Guide"

"Sad Isn't Bad: When Someone You Love Dies"

"What Happens When Someone Dies? A Child's Guide to Death and Funerals"

Judging by the nods around the table, everyone agreed. All were convinced that dire consequences would result if they were asked to help pediatric palliative care patients.

We looked at each other and smiled. We had to empathize. "We have every confidence in your ability to effectively work with children," we told them. "Let us tell you about a few of them that made a difference in our health care ministry."

Sr. Maxine began:

"When I was assigned to work as the chaplain to our youngest patients and their families, I was anything but thrilled. I worried that I wasn't tough enough to help babies and children — and their suffering parents. I just knew that I would feel too deeply and become a hindrance instead of a help.

"What neither of us counted on, as the team's nurse specialist and the chaplain, was that the children and their parents would become our best teachers. These children and their parents would prod us to listen and to pray. They taught us three fundamental truths about pediatric palliative care."

TRUTH #1

CHILDREN AND ADOLESCENTS HAVE A DEEP INNATE SPIRITUALITY

Children, even babies, have an innate spiritual life. This spirituality is a relationship with someone bigger than themselves. It opens the door to relating to those who care for them, sharing their worries and letting the light shine through. In his book *The Spiritual Life of Children*, child psychiatrist Robert Coles concluded that children are involved in making sense of their world from the time they are conscious of their separateness between themselves and their environment — which is roughly the age of a young toddler.¹ James Fowler's book, *Stages of Faith: The Psychology of Human Development and the Quest for Meaning*, explains that children as young as 2 years old have an intuitive faith which grows as imagination develops.² Jesus assures us that children are especially close to God the Father: "See that you do not despise one of these little ones, for I say to you that their angels in heaven always look upon the face of my heavenly Father." (Matthew 18:10)

DAN'S STORY

As told by Sr. Maxine

Dan was 15 when he was diagnosed with cancer. We had been with Dan during the ups and downs of the next three years. He wanted to live. He tried every treatment recommended to him, even clini-



cal research trials. Dan's aunt was a friend of mine, and every month or so she would have a group of us over to have dinner with Dan. We would eat and play cards and talk about how he was doing.

Dan was smart. During the time we knew him, he graduated from high school and began college. He knew when he was dying, and he told us he was glad he had tried "everything." Dan's family described themselves as Catholic, although he and his parents did not attend Mass. Dan was never baptized. He did speak about God, saying, "I know God will give me the strength to get through this."

Dan's last hospitalization was difficult. He was very tired and couldn't talk much. His mom was quite fearful about losing her son, and she also was afraid for him because he had never been baptized. Dan's aunt called me and asked me to talk with Dan about baptism.

Our visit had short conversations and long, comfortable silences. Dan told me, "I know God loves me and watches out for me. I believe in heaven and I'm going there ... but I don't know about baptism. I don't want to hurt my mom, but ..."

I explained the sacrament to him as a continuing relationship with God.

"Do I have to?" he asked.

"No," I said, but I explained the short ceremony and how everything could be brought to his bedside. Dan started to sleep again. I stood to go.

"Thank you for being such a good friend," I said.

Dan opened his eyes. "I do not want to be baptized," he said, "I don't want to disappoint my mom, but I don't see the need."

We could feel right about his decision. Dan experienced baptism of desire long before our conversation. He knew his Creator, they shared life together through thick and thin. He experienced love, and he trusted the one who is greater than himself. Dan was right with God.

Dan died a few days later at home with hospice. His aunt, his parish priest and I talked and prayed with his mother. His mom came to a sense of peace with his decision. Dan's innate spirituality and his family's love led him to a secure sense of relationship with God when he died.

TRUTH #2

CHILDREN AND ADOLESCENTS HAVE A PROFOUND TRUST IN GOD

This does not mean that children do not have fear.

They do. Children fear pain, separation and abandonment from those they love. Just like everyone else. Rather, this trust is openness to expressing their fears. It can also show itself in protective feelings and gestures toward those whom they perceive as vulnerable — sometimes their parents, and sometimes even their health care providers.

Children are in tune with their environment. When they trust so deeply, they don't feel shame in asking for help and comfort. They know who understands and who is safe to talk to. Dr. Anne Grinyer, a social researcher, has observed that ill children are more concerned with process, whereas adults are most concerned with outcome.³ When confronted with illness, adults hope

Children are in tune with their environment. When they trust so deeply, they don't feel shame in asking for help and comfort.

for a cure; children are more attuned to how hospital personnel respond when asked for a listening ear or a hug, whether the pediatric unit has a child life department that understands the value of play and if their friends and family are allowed to visit any time they want.

Jesus' teachings are a wonderful example of the importance of this unshakable trust and our appropriate response to it: "'Let the children come to me; do not prevent them, for the kingdom of God belongs to such as these. Amen, I say to you, whoever does not accept the kingdom of God like a child will not enter it.' Then he embraced them and blessed them, placing his hands on them." (Mark 10:14-16)

MAGGIE'S STORY

As told by Beth White

Born with multiple congenital anomalies, Maggie spent the first year of her life in and out of a children's hospital 50 miles from her home. When Maggie was born, her mom was told to "take her home and love her. She won't live very long."

Our team first saw Maggie when she was 7 years old. She weighed 23 pounds, and her contracted body prevented her from sitting up alone. Respiratory and nutritional problems made her a frequent patient in our hospital, and Maggie struggled with skin breakdown around the feeding tube she required because she couldn't eat enough by mouth to survive.

But could she ever talk! She made up in verbal ability what she lacked in physical skill. Maggie knew everyone on the nursing unit, and we all knew her. She had her favorite nurses and chaplains and would call to us from her room.

Actually, Maggie had another verbal skill that she only showed during painful treatments — treatments we all disliked — such as dressing changes. Maggie could swear. Maggie's swearing would make a sailor blush. She was the most creatively vulgar patient we had ever heard, adult or child; she was terrified of the treatments' pain and assault to her body.

Our palliative care team was able to work with the physicians to help control her pain, but no matter what distractions the nurses and child life therapists and chaplains tried, Maggie's primary coping behavior was swearing. When the treatments were over, though, Maggie's personality returned. She would pat our arms and comfort those who hurt her. "That's OK. I love you. It's all over for now," she would say.

Maggie attended church in her hometown when she was well. She loved to sing, and one of her favorite songs was "Amazing Grace." She could sing as loudly as she swore. When her pastor visited, they would sing together and bring tears to the eyes of everyone who heard. Maggie railed against her fear of pain by yelling at God. But she always had energy left to comfort others with the full assurance of God's amazing grace.

TRUTH #3

NO ONE CAN DO THIS ALONE

The popular phrase is, "Life is a team sport." In pediatric palliative care, that is more than a casual comment, it is an essential truth.

Effective pediatric palliative care requires a team. Team members bring different skill sets to support pediatric patients and their families. Palliative care focuses on symptom management and quality of life. When serious or life-threatening illness occurs, it is often the chaplain who has the time to listen to the intense worries of parents, who can assure children that they are understood spiritually. It is the chaplain who understands the stresses of the doctors and the nurses who care for sick children. It is the chaplain who is most readily recognized as showing God's unconditional and reassuring love. Chaplains hold the hope for quality of life under the most trying circumstances.

When serious or life-threatening illness occurs, it is often the chaplain who has the time to listen to the intense worries of parents, who can assure children that they are understood spiritually.

Optimal palliative team membership is interdisciplinary. Our team includes a physician, nurses, a chaplain, a tutor, a counselor and a scheduling and data coordinator. King Solomon wrote, "Two are better than one: they get a good wage for their labor. If the one falls, the other will lift up his companion. Woe to the solitary man! For if he should fall, he has no one to lift him up ... A three-ply cord is not easily broken." (Ecclesiastes 4: 9-12)

MIRACLE'S STORY

As told by both

When a parent learns her baby will be born with a serious, life-threatening birth defect, our high-risk obstetric physicians often consult our maternal-child and pediatric palliative care team.

Trisha was a 22-year-old expectant mother who learned that her baby girl would be born with a lethal birth defect. The baby was not expected to live more than a few hours after birth.

Trisha met our team the day she learned about the baby's diagnosis. She sat stoically as we tried to talk with her about her feelings and offer her support. She did not talk. Every two weeks, Trisha came for her doctor's appointments, and each time a member of our team met with her. Trisha's speech was limited to polite, one-word answers to our questions. We learned that the baby was named Miracle.

Tricia seemed to accept our team members, so we kept coming. When our counselor mentioned that planning ahead can sometimes make a terrible situation more meaningful, Trisha spoke: "What can be planned?" Our counselor explained that planning for Miracle's birth could help Trisha and those she loved make the most of the baby's life, no matter how long it was.

Trisha gradually shared with us what she wanted when Miracle was born, and our team nurse coordinated the plan. Trisha's preferences were passed along to all hospital units and staff members who would care for Trisha and Miracle. A private room was prepared. A special outfit was picked out. Chosen family members were invited



in to hold the baby, and a volunteer professional photographer took pictures. Sr. Maxine was asked to baptize Miracle, and the entire family held her.

Miracle was given life for one hour. She died peacefully in her mother's arms. This baby touched the lives of her family, and through their persistence, our interdisciplinary team was able to create the setting in which a mother could express her love and grief.

SOURCES OF SUPPORT

Health care professionals who choose to care for persons with life-threatening illnesses and their families cannot engage in this work without needing support themselves. The risk of spiritual anxiety is high when death is frequently encountered. This is especially true when the serious illness or death is "unfair" or "not normal," as when the patient is a child. Maintaining balance and perspective can be a challenge.

Yet, we both submit that working with very ill children can be uplifting. As Dan, Maggie and Miracle show, children are open, honest and willing to express their feelings. Adults' feelings are more muffled. Their reluctance to talk and fear about dying is common. This is understandable. The unknown and the permanence of separation from earthly life justifiably produce anxiety. Adult worries about dying can make even committed Christians wonder, "If everyone else is so scared, maybe I should be too."

Children's openness can lift the burden from us. Obviously our human expectations are not met when a child dies. Lost potential, lost dreams and incomplete human development are tragedies. But children and adolescents reflect hope and trust even when facing death. Very ill children have helped us understand that we all have a purpose, no matter the length of our life. When we talk with children, we do not have to worry as much about how to bring up sensitive topics. Their faith and trust in God is so straightforward that they help us reaffirm our belief in the resurrection.

Further, although caring for parents who have very sick and dying children can be some of the saddest work in health care, parental love can help resolve spiritual uncertainties in pediatric palliative care. Parents love their children, often more than they love anyone else. Parents want to do what is best for their children, to make medical decisions directed to helping their children achieve the best outcome. God loves us in the same way. Listening to parents has shown us the presence of God.

Our *Ethical and Religious Directives for Catholic Health Care Services* give us additional support. We are to provide care that "assists those in need to experience their own dignity and value, especially when these are obscured by the burdens of illness or the anxiety of imminent death."⁴

"You won't be alone," we assured our class of future health care chaplains. "We will discuss your experiences and your feelings privately and as a group. We will walk with you throughout this experience. We are in this together."

Working with seriously ill children and families gives meaning to life. Parents, children and adolescents help us develop a clearer perspective of what is really valuable. Families of all ages help us to grow and develop as both persons and professionals. Thinking about our own mortality, limitations and vulnerabilities does not need to lead to spiritual doubt. We will never have all the answers while living on this earth, but we can live fully and joyfully in spite of that. Living in the hope of life's mystery brings great comfort. Working with very sick and dying children and families teaches these lessons well.

SR. MARY MAXINE YOUNG, SND, is chaplain for both the maternal-child and pediatric palliative care and adult palliative care teams at Mercy St. Vincent Medical Center/Mercy Children's Hospital, Toledo, Ohio. Mercy is a member of Catholic Healthcare Partners.

BETH E. WHITE is a pediatric clinical nurse specialist. She is presently the nursing tutor at Mercy College of Northwest Ohio in Toledo.

NOTES

1. Robert Coles, *The Spiritual Life of Children* (Boston: Houghton Mifflin, 1991).
2. James W. Fowler, *Stages of Faith: The Psychology of Human Development and the Quest for Meaning* (New York: HarperOne, 1995).
3. Anne Grinyer, "Contrasting Parental Perspectives with Those of Teenagers and Young Adults with Cancer: Comparing the Findings from Two Qualitative Studies," *European Journal of Oncology Nursing*, 13 (2009): 200-206.
4. United States Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, Fifth Edition, (Washington, D.C.: USCCB, 2009). (Part II: Pastoral and Spiritual Responsibilities of Catholic Health Care).

JOURNAL OF THE CATHOLIC HEALTH ASSOCIATION OF THE UNITED STATES

www.chausa.org

HEALTH PROGRESS®

Reprinted from *Health Progress*, May-June 2011

Copyright © 2011 by The Catholic Health Association of the United States
