

# Perinatal Hospice: A Holistic Approach for When Death Comes at the Beginning of Life

By Amy Kuebelbeck

A new frontier in the care of the dying is breaking open where death is expected least—at the beginning of life.

As prenatal testing becomes increasingly sophisticated and routine, more parents are learning devastating news before their babies are born. In too many places, the ability to diagnose a fatal condition has raced ahead of the ability to care for these families and their babies. But in a beautiful and practical response, a few hospitals around the country are starting perinatal hospice programs for families who wish to continue their pregnancies with babies who likely will die before, during, or after birth.

Under the conventional hospice model, services do not begin until the baby is born or is discharged from the hospital, which is of little help when a baby has a life expectancy of hours or even minutes. Perinatal hospice, in contrast, is intended to support families from the time of diagnosis, when their grief journey begins. In the words of one perinatal hospice program, **Deeya** (Sanskrit for “a small light”), based at Children’s Hospitals and Clinics in Minneapolis: “We walk with families through pregnancy, birth, life, and bereavement — supporting the dignity and value of each life.” It is a tender, life-affirming response to one of the most heartbreaking challenges of prenatal testing.

Hoeldtke and Calhoun (2001) proposed a perinatal hospice model that incorporates perinatal grief management and hospice care. They recommend using a multidisciplinary team approach — including anesthesia service, labor and delivery nurses, social workers and chaplains — to care for the family before, during, and after birth.

Perinatal hospice now is offered through San Diego Hospice and Palliative Care; Cincinnati Children’s Hospital Medical Center; Kansas City Hospice; Texas Tech University Health Sciences Center, El Paso; Angel Babies of Hinds Hospice, Fresno, California; and others.

Even in areas without a formal program, caregivers can offer care in the spirit of hospice. During the remainder of the pregnancy, for example, caregivers can provide frequent ultrasound pictures for the parents to keep, help draw up specialized birth plans, and offer support for parents’ grief. Once the baby arrives, caregivers can help families keep the baby comfortable if the baby is still alive, help families take photographs (Hochberg, 2003), collect handprints and footprints and locks of hair, bathe the baby, perhaps rock the baby and sing or read to him or her, and invite family members and close friends to see the baby and enter into the bittersweet circle (Catlin & Carter, 2002).

This approach is part of a marked improvement under way in practices surrounding stillbirth and infant death. As the late Dr. Elisabeth Kübler-Ross said in 1986,

“Our present Western society is not willing to experience death, in the sense that it is hidden by a conspiracy of si-



lence. The sudden and unexplained death of a baby is very tragic, yet it is not regarded as something to be sad over, especially if the baby has never lived. As a consequence, parents are often not given permission by family or friends to mourn the death of their baby, and they are very often left alone in an apparently unsympathetic world, not knowing how to feel and not knowing how to cope.”

Although the death of a baby before or after birth is not uncommon, for decades it was shrouded in silence. Parents typically were not allowed to see their baby and were advised to forget about it and have another one. An obstetric nursing textbook from the 1950s (Bookmiller & Bowen, 1956) said nothing about how to care for parents experiencing stillbirth or neonatal death, but it did refer to babies with birth defects as “monsters.” “Parents should not be allowed to see monstrosities,” (pg. 663) the authors wrote. Even into the 1980s, many hospitals still prohibited parents from seeing or holding their stillborn babies (Peppers & Knapp, 1980). Too often, the babies were never spoken of again.

We are now starting to see a significant cultural shift in which parents are being allowed to acknowledge and grieve for a tiny child who has died. Driven by persistent efforts beginning in the 1970s by bereaved parents and organizations such as National SHARE Pregnancy and Infant Loss Support Inc., many hospitals have adopted more sensitive practices and offer support groups and counseling for grieving parents. Perinatal hospice builds upon these efforts.

Caregivers who may view continuing a pregnancy following a lethal prenatal diagnosis as an exercise in futility or denial may wish to reconsider. A recommendation to “get it over with” overlooks hard-won understandings about death and dying, hospice care and bereavement. There is no shortcut through grief, as much as contemporary society would wish there to be. Parents who continue their pregnancy receive the gift of time for anticipatory grief, and they can find solace in the knowledge that they protected their baby and gave their baby — and themselves — the gift of a peaceful, natural death. And parents may receive greater understanding and support from family and friends, who otherwise may dismiss a terminally ill but unseen baby as simply a forgettable accident of nature. If parents are given the option of continuing the pregnancy and are assured that they will not be literally or figuratively abandoned by medical staff, many parents instinctively want to embrace whatever time they may be able to have with their baby, even if it is only before birth.

My interest in this nascent effort is firsthand. I was five-and-a-half months pregnant when my husband and I learned that our son, Gabriel, had an incurable heart condition. Despite some wrenchingly aggressive surgical options, no one could give our son a good heart. So we set out to give him a good, although brief, life.

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Although no perinatal hospice existed in our area at the time, much of what we did was in the spirit of hospice. What ensued was an extraordinary journey of grief, joy and love as we waited with Gabriel. During that gift of time, we prepared for his birth, prepared for his death, and embraced his life. Our baby lived for nine months before he was born and for two-and-a-half peaceful hours afterward. During his gentle transition from life to death, he was cradled by my husband and me, and surrounded by a roomful of people who loved him. As we inscribed on his gravestone, he knew only love.

So I can strongly affirm this assessment from Calhoun and Hoeldtke (2000): "Parental responses have been overwhelmingly positive," they report. "These parents are allowed the bitter-sweetness of their child's birth and too-soon departure. Grief lessens as time passes and parents rest secure in the knowledge that they shared in their baby's life and treated the child with the same dignity as a terminally ill adult." ■

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### About the Author

*Amy Kuebelbeck is a former journalist and author of Waiting with Gabriel: A Story of Cherishing a Baby's Brief Life, Chicago: Loyola Press (2003). Her newborn son, Gabriel, died in 1999 of hypoplastic left heart syndrome. She writes from St. Paul, Minnesota.*

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