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## A Gift of Time

CONTINUING A PREGNANCY WHEN A BABY'S LIFE IS EXPECTED TO BE BRIEF

By Amy Kuebelbeck

Not long ago, it wasn't possible to know before birth that a baby would be born with a life-limiting condition such as anencephaly, Trisomy 18, or Potter's syndrome. With advances in prenatal testing, many conditions now can be detected relatively easily before birth. But then what? Terminating the pregnancy, of course, is one option. In many places, that course of action is recommended and expected. But a significant number of parents search for a different path. As perinatal social workers, how can you support patients who wish to continue their pregnancies and embrace whatever time their baby is able to have, within the womb and without?

This relatively new phenomenon is inspiring a new response: perinatal hospice and palliative care, which is an innovative and compassionate model of support that can be offered to parents who learn during pregnancy that their baby has a life-limiting condition. This support is a model of caring for the family from the time of diagnosis—before, during, and after

birth. It can easily be incorporated into standard pregnancy and birth care.

Perinatal hospice is not a place. It is more a frame of mind. It can be thought of as "hospice in the womb" (including birth planning and preliminary medical decision-making before the baby is born) as well as more traditional hospice and palliative care at home after birth (if the baby lives



longer than a few minutes or hours). Palliative care can also include medical treatments intended to improve the baby's life. This approach supports families through the rest of the pregnancy, through decision-making before and after birth, and through their grief. Perinatal hospice enables families to make meaningful plans for the baby's life, birth, and death, honoring the baby as well as the baby's family. It is a beautiful and practical response to one of the most heartbreaking challenges of prenatal testing.

The concept was coined in 1995 by Drs. Byron Calhoun and Nathan Hoeldtke, who drew upon the concept of adult hospice care, a movement begun by Cicely Saunders in Great Britain in the 1960s to address a lack of care for the dying. "We propose a

model of care that incorporates the strengths of prenatal diagnosis, perinatal grief management, and hospice care to address the needs of these families," Calhoun and Hoeldtke wrote, describing a team effort that would include maternal-fetal medicine subspecialists, obstetricians, labor and delivery nurses, and many others.<sup>1</sup> Perinatal social workers can provide an essential link in this chain of care.

Caregivers can provide support during pregnancy, including assisting with birth planning, making medical decisions for the baby, offering support for anticipatory grief, and thinking about experiences with the baby both before and after birth. And then caregivers can provide support when baby arrives, helping parents create memories, including extended families, and supporting families as they say goodbye. It's also important to note that some babies surprise everyone and are able to live longer than expected. Babies with the same diagnosis can vary greatly in their ability

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Amy Kuebelbeck edits *perinatalhospice.org*, a clearinghouse of information about perinatal hospice and palliative care. She wrote *Waiting with Gabriel: A Story of Cherishing a Baby's Brief Life* (Loyola Press, 2003), a memoir about her own experience, and she is lead author of *A Gift of Time: Continuing Your Pregnancy When Your Baby's Life Is Expected to Be Brief* (Johns Hopkins University Press, 2011), co-authored with Deborah L. Davis, Ph.D.

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to sustain life. They are individuals, not diagnoses. Caregivers can provide support as events unfold and as new decisions may arise, helping the family follow the baby's lead.

The concept fits well with the general definition of palliative care from the World Health Organization, which describes it as care that improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, along with spiritual and psychosocial support from diagnosis to the end of life and bereavement.<sup>2</sup> According to the WHO, palliative care "affirms life and regards dying as a normal process" and "intends neither to hasten or postpone death," principles that align well with families choosing to continue these pregnancies.

How many parents actually do this? One early report, written before the spread of perinatal hospice and palliative care, estimated that about 20 percent of parents chose to continue their pregnancies—even in the absence of support.<sup>3</sup> But the percentages increase dramatically when parents are offered perinatal hospice support and reassured that they will not be abandoned by their caregivers. In one British study, when parents were offered perinatal hospice as an option, 40 percent chose to continue.<sup>4</sup> In a U.S. study, when parents were given the option of perinatal hospice, the number rose to 75 percent.<sup>5</sup> And in another U.S. study, the number who chose perinatal hospice was 85 percent.<sup>6</sup> Even if the overall numbers are small, these parents need and deserve best-practices care. The need is likely to continue to grow, especially as testing continues to advance and as awareness spreads. Parents are hearing about perinatal hospice and palliative care through the Internet, through other parents, and through significant coverage in major media, such as a front-page story in *The New York Times*,<sup>7</sup> a lead story on MSNBC.com,<sup>8</sup> and many others.<sup>9</sup> The topic has also been addressed by numerous articles in medical jour-

nals<sup>10</sup> as well as health-related media such as the Canadian Medical Association Journal.<sup>11</sup>

Some might question why parents would put themselves through a pregnancy like this when there's no hope. I—and other parents who have traveled this path—invite skeptics to consider that parents can find different kinds of hope. They may hope the baby is born alive. They may hope that the baby be loved. They may hope that the baby be remembered. Those are profound kinds of hope. Parents who have chosen perinatal hospice have said that this kind of care helped their hopes be fulfilled. Continuing the pregnancy is not about passively waiting for death; it is about actively embracing the brief, shining moment of this little life. It is a beautiful, rational, healing choice.

Initial concerns often revolve around the mother's physical and emotional health. Small studies indicate that these pregnancies are often otherwise physically normal for the mother,<sup>12</sup> and abortion poses physical risks of its own, especially later in gestation.<sup>13</sup> In an era of evidence-based medicine, it's important to note that there is no research to support the presumption that terminating the pregnancy is easier on the mother psychologically. In fact, research to date suggests the opposite.<sup>14</sup> Termination is not a shortcut through grief. Another major concern for most parents is whether the baby will suffer during pregnancy or after birth. Many life-limiting conditions are not inherently uncomfortable for the baby. (See *A Gift of Time: Continuing Your Pregnancy When Your Baby's Life Is Expected to Be Brief* for parents' poignant descriptions of their baby's peaceful life and death.) If pain is a possibility, it can be treated aggressively and effectively, and pain can be avoided altogether by careful decisions about medical intervention. A terminally ill baby does not have to be rushed to intensive care or surgery or a ventilator. Parents can even decline minor routine procedures such as standard newborn shots and tests that would cause unnecessary

discomfort. The baby can instead be enveloped in comfort and love.

Perinatal hospice and palliative care also reflect newer understandings about caring for parents experiencing perinatal loss. Outdated practices forbade parents from seeing a baby who was dying or stillborn. Into the 1980s and even later, caregivers often advised parents to forget about it and have another one, and babies' bodies often were disposed of as medical waste. A baby's death was treated as a clinical and fleeting medical incident. These practices may have become routine out of compassion, to try to protect parents (and perhaps caregivers) from painful situations. Yet parents and caregivers eventually realized that these practices hurt rather than helped. They failed to honor the baby or the parents. Many hospitals have now adopted more sensitive practices. For example, caregivers now often encourage parents to see their baby, hold their baby, collect handprints and footprints, take photographs, and generally help to acknowledge that this is a real baby and this is a real loss. Babies' bodies are cared for tenderly and buried or cremated with respect; parents' grief is considered a healthy, normal response; and the baby is recognized as a unique, irreplaceable child. Now we have a new population of patients, created by advances in prenatal testing. This is an opportunity for a new kind of care that incorporates newer understandings and avoids repeating mistakes of the past.

Perinatal palliative care is an appropriate option for patients whose babies are diagnosed prenatally with conditions that are unquestionably lethal. It's also appropriate for families who are faced with decisions about aggressive medical intervention. That decision is often framed as "saving your baby" vs. "doing nothing." What parent wants to do nothing? But palliative care is not nothing; it's a different kind of care. It can include palliative measures that may extend life or make life more comfortable for the baby. Some families are looking for a third way, another option besides termination or massive intervention. Perinatal hospice offers a third way.<sup>15</sup>

Fortunately, perinatal hospice and palliative care programs are forming to meet this need. More than 150 pioneering hospitals, hospices, and clinics in the U.S. and around the world are now listed on *perinatalhospice.org*. As of this writing, support is available in 36 U.S. states as well as in Australia, Canada, England, France, Ireland, Italy, New Zealand, Nicaragua, Norway, Poland, and Spain.

For many NAPSW members, the concept of perinatal hospice and palliative care is not new because they are already offering this important care to their patients. On behalf of parents, I extend my gratitude to these pioneers. For those who haven't yet ventured into these waters, it is likely that patients will come your way hoping—or expecting—to be supported well through a pregnancy like this. Many resources for starting a program are available,<sup>16</sup> including a Perinatal Palliative Care Toolkit and position paper on perinatal palliative care<sup>17</sup> from RTS Bereavement Services at Gundersen Lutheran Medical Foundation<sup>18</sup> and a framework for perinatal palliative care from the British Association of Perinatal Medicine.<sup>19</sup>

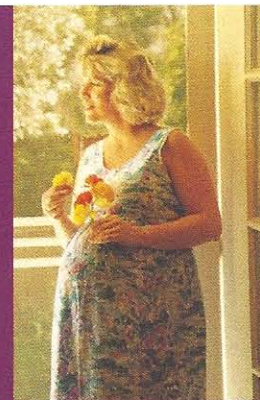
Dr. Calhoun describes parents' reaction this way: "Parental responses have been overwhelmingly positive. These parents are allowed the bitter-sweetness of their child's birth and too-soon departure. Grief lessens as time passes and parents rest secure in the knowledge that they shared in their baby's life and treated the child with the same dignity as a terminally ill adult."<sup>20</sup>

And in the words of one of more than 100 parents who shared their experiences for *A Gift of Time*:

*"By giving my son the protection of my body to face the announced death, I was giving him life, all of his life, so that it would be recorded in our family, in all of our history, and in the hearts of each of us. It wasn't a morbid walk but a formidable surge of love."*

—Isabelle<sup>21</sup>

*Continuing the pregnancy is about actively embracing the brief, shining moment of this little life*



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