Book Review

Gift of time: Continuing your pregnancy when your baby's life is expected to be brief
by Amy Kuebelbeck and Deborah L. Davis. Baltimore, MD: The Johns Hopkins University Press, 2011. xiii + 391 pp.

Amy Kuebelbeck is an author and mother. She is a journalist who previously worked as a reporter and editor for the Associated Press. She is the author of the book *Waiting with Gabriel*, the story of her journey with her son Gabriel, who was diagnosed prenatally with hypoplastic left heart syndrome and lived only a short time after birth. She writes from personal experience about perinatal hospice and brings together the stories of over 120 mothers and fathers who experienced a baby with a lethal anomaly. Amy writes with Deborah L. Davis, who is a developmental psychologist and an expert in neonatal medical ethics and perinatal bereavement. Her work includes the book *Empty Cradle, Broken Heart: Surviving the Death of Your Baby*. What results from their collaboration is a practical, personal, readable, and encouraging book about how to deal with perinatal loss and stillbirth due to lethal anomalies. The whole concept of perinatal hospice is fleshed out and explained. Most importantly, the book encourages parents to relish the special time they will have with their child.

Chapter 1 sets the stage by describing how advanced prenatal diagnosis has become in the last 15–20 years. Everyone expects a “normal” pregnancy. The diagnosis of a pregnancy with severe problems brings devastation to families. The plethora of diagnostic testing is bewildering and may be frightening to many couples. The wisdom of seeking good

counsel and medical care is emphasized. The couples share how they received the news and how important to them it was that the news be shared in a gentle, loving, and compassionate face-to-face encounter. Couples were scarred by brusque demeanors, and one couple even learned from an answering machine! The swirling of emotions around the diagnosis may range from disbelief to anger. There may be confusion, even confusion with regard to their relationship as a couple. All of these issues are explored by the families who share their stories.

Chapter 2 turns to the most difficult part of the discussion: “What now?” Kuebelbeck and Davis explore all the various options and how the decision will affect the families forever. The couples share how emotionally and spiritually wrenching the decision of what to do in the pregnancy really is. Many of the couples were offered only termination and not hospice. They discuss the pressure to terminate pregnancies with lethal anomalies; many couples found the pressure to be intense. Many caregivers are not aware of perinatal hospice. Kuebelbeck and Davis share this loving concept with clarity and compassion. They encourage families to seek more information. There are good programs in palliative care, and readers are informed of them. Couples and families are further counseled to gather information about their baby’s condition and prognosis. Also, sharing with another couple who has had a child with the same

condition is useful to help parents understand what they will be going through. Suffering is also discussed. Parents may be reassured that their baby with a lethal anomaly is not suffering *in utero*. Kuebelbeck also gives a brief overview of the termination techniques, including surgical abortions and medical abortions which generally involve labor. The authors also discuss risks of maternal death, which are higher in abortions done after 21 weeks; the significant mental health effects that result from abortion; and the spiritual, religious and ethical considerations of such decisions. The families share what was and was not useful regarding the information. Finally, the need to seek input from partners and wise counselors was emphasized by the parents. The decision to continue the pregnancy gives parents the most important gift of all: "the gift of time."

Chapter 3 moves into the "emotional journey" of the pregnancy with a looming death. The anticipatory nature of grief for dashed hopes is brought forth. The stages of the grieving process are described, and the parents movingly write of how their grief affected their lives. The conflicting emotions and thoughts pop up in the parents' minds. Some couples felt guilt, failure, and anger in the process. Kuebelbeck gives voice to their frustrations. Fears are openly discussed by the parents: fears of the unknown, fears of the baby suffering, fears of childbirth, fears about the baby's appearance, and most importantly fears about death. The authors describe multiple, pragmatic ways to cope with the emotions. Among the methods discussed are mindful acceptance; imagining meeting your baby; planning special experiences with your baby; longer ultrasound appointments; physical care; spending time in nature; etc. One of the most critical areas explored is how to include the other children in the whole

pregnancy and where to find sibling support for them. Kuebelbeck and Davis also give voice to the wonderful message of God to these families about His love for them even while they are questioning why these things happen. The families help others to understand what "living in the twilight of death" means with a child who will die soon after birth. The parents talk of reclaiming hope and how to become comfortable with their role as parents of a terminally ill baby.

Chapter 4 covers the practical aspects of how the pregnancy will progress. There is an extensive discussion of how to interact with others. The couples share their experiences about explaining their situation to others and why they chose to carry on with their pregnancy. Some parents chose to discuss the ways in which they interacted with family members. They described reactions and support. Others were dismayed that people were silent. Kuebelbeck and Davis note that often people withdraw from a painful situation, not knowing what to say or do. Families sometimes found people questioning why they would continue to carry a baby with a lethal anomaly, even to the point of actually making harsh comments. Kuebelbeck responds that when people are concerned, they may make mistaken statements about suffering. There are even families who deny the diagnosis of the baby and think couples are being dramatic. Furthermore, some responses are completely unhelpful, and couples need to be prepared to deal with them. The subject of how to deal with another person's pregnancy and newborn is even mentioned. The chapter shows with how to find support in practical ways. The couples who participated wrote about the most helpful things to do. Other bereaved parents are a great resource. Some couples may benefit from professional counseling. Lastly, the chapter ends with how to find

good perinatal hospice care, prenatal care, and coordinating care. Details of planning for the birth are listed and include: naming the baby, a birthing plan, pregnancy photographs (and post-delivery), and keepsakes.

Chapter 5 tackles the tough decisions about the care of your baby with a shortened lifespan after delivery. Research into the specific diagnosis is helpful in understanding the prognosis and helps to tailor the care. The authors discuss what the couples needed to know about medical interventions, life support, ambivalence, outside advice, the “wait & see” approach, palliative care, nutrition and hydration, pain relief, and resuscitation. Each area is explored thoroughly, and examples are provided by the families. The most important aspects of the chapter are that the families are allowed to engage in the care of their child and work through the expectations for their baby with their care providers. A good birth plan formed in consultation with the obstetrician, the labor and delivery team, and the neonatal team eliminates almost all the troublesome and adversarial aspects of caring for the baby. Finally, it allows the siblings and extended family an opportunity to be involved in this special care.

Chapter 6 considers the major topic for the family who chooses to undergo perinatal hospice: the birth, life, and death of their baby. The chapter provides great insight and detail from families about how to accomplish this loving act. Central to this process is the birth plan, which may be as simple or elaborate as the family wishes. It allows the family to share their views with the care givers about labor, the delivery process, attendance of support people at the birth, care of the baby, the type of delivery, fetal monitoring in labor, where to give birth, and neonatal resuscitation. The book shares how helpful it is to have a meeting or consultation with the

neonatal team and/or labor and delivery personnel to clarify the family's wishes. Spiritual aspects after birth are discussed, including baptism, blessing, naming, and even circumcision. There is emphasis on planning prior to the birth so that the family's pastor, priest, or rabbi is available. The couples share how pre-planning about keepsakes, photographs, sibling presence, and family presence and support are keys to making the most of their time with their baby. Planning for the funeral and burial is recommended prior to the birth of the baby. The details of the funeral can be discussed and planned, and significant individuals can be included in the baby's service. Details about burial can be finalized.

Chapter 7 consists of the most poignant writing in the book as parents share the stories of the births of their little ones. Parents share that many of these infants were born prematurely. Others write of how anxious they were about the planned delivery. Kuebelbeck even writes about stillbirth and what to expect with the death of a child prior to delivery. In labor and delivery, parents may still need to advocate for themselves and their little one. The couples describe the conflicting emotions with labor. The pregnancy is about to end, and tragically, so is their baby's life. The baby has been safe in the womb. The time has come to be born and die soon after birth. Pain relief should be arranged and even what will happen if an induction does not work well. The most powerful moment will come, according to the parents, at the birth of this special baby. Usually, the delivery team is in awe of the love of the parents for this child. Seeing the baby for the first time remains a powerful image to the parents. They note the beautiful characteristics of their baby and do not see any imperfections. Photographs are mentioned again to document the birth. Time with family and

friends may be part of the process. Parents may be allowed extra time to feed, soothe, and sleep with their baby. Some babies may even go to the intensive care unit if that is part of the plan, and parents need to be prepared for that journey. The book even helps couples with how to deal with their baby possibly going home with them for a short time. If their baby ends up going home, the families share the need for sibling involvement, planning medical decisions in advance, palliative care, family and friends, and coming to terms with the still shortened life.

Chapter 8 could be the entire book in itself. So much practical wisdom is packed into this chapter about how to “say goodbye” to your baby. Everything about the loss of the couples’ babies is covered. Kuebelbeck and Davis prepare families by gently describing the dying process, the varying death experiences of the babies involved, the moment of death, death at home, death in unexpected circumstances, discontinuing medical interventions, and care if the baby struggles. Kuebelbeck does not shy away from the spiritual aspects of the loss of a child. Couple after couple described the peace that came with the passing of their child and the awareness that their child was going to be with Jesus in peace and rest. The toughest aspects of the loss of a baby include the physical care of the baby’s body, the appearance after death, keeping the baby with the parents after death, time with family and friends, photography, autopsy, and organ donation. Finally, the authors round out the chapter with leaving the hospital, transport of the baby’s body, funeral/memorial services, size of service, siblings, visitation, eulogy, carrying the casket, and burial.

Chapter 9 deals with the postpartum recovery of the mother as well as the process of grieving for the loss of a child. Many different suggestions for how to

deal with the grief are discussed. Time and the support of others are critical. Kuebelbeck notes there will be various experiences: letting go, complex and intense grief, variations in the length of grief, uniqueness to the grief, shock, numbness, denial, mistaken responsibility/guilt, anger, emptiness, and a sense of vulnerability to tragedy. Couples are encouraged to make time for their relationship. Siblings need to know they are still important and loved. There may be challenges in reconnecting with people outside the family and sharing what happened. Parents struggle with seeing other pregnancies and babies. They know it will take time to be able to deal with the issue. Finally, future pregnancies are discussed frankly in the context of fear of having another child die or another child with problems.

Chapter 10 consists of the significance and joy each one of these children brought to their families. Every couple believed that they had done the right thing by continuing the pregnancy; they did not regret one moment of time they shared with their little one. The couples reflect on finding peace and meaning, their baby’s place in the family, their baby’s impact on the world, and their gratitude for the life well lived by their baby. Amy Kuebelbeck says it well, “Perinatal Hospice allows parents to just be parents.”

This book is highly recommended and is suitable for all medical professionals. It will be helpful in your practice to recommend it or provide it to families in similar situations.

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