

Doula Care and Twin Loss

by Amy Hodge

September 2001. I am lying on my side on a gurney in an OR. Banks of lights blaze while nervous onlookers wait in hushed silence. Paul, my husband, and Kerry Dixon (CPM/LM), our doula, reach for me and I crush their hands. Our twins are about to be born.

It has been a grueling pregnancy. We had waited years for these babies. Identical twins were such a surprise and so welcome. Early on, the excitement of twin pregnancy waned as things began to go terribly wrong. I was a crumpled heap on the couch due to nausea and bleeding. My heart began to race. I had dizzy spells and eventually didn't trust myself to drive. The movements of the twins reassured me, but at the same time, my abdomen grew far too quickly and appeared lopsided. Doctors where I live shook their heads. We did some research and got in the car.

After a six-hundred-mile drive, we arrived in Minneapolis, Minnesota. A diagnosis of Twin-to-Twin-Transfusion Syndrome confirmed what this mother's heart had known all along. The babies were in serious trouble. TTTS is a placental pathology that occurs in 10% of identical twinning. Perfectly normal babies share a placenta in which blood vessels are connected. One baby, the recipient, gets too much blood at the expense of her twin, the donor. For babies who develop TTTS at mid pregnancy, the death rate without treatment may be as high as 80 to 100%. Maternal malnutrition is a common complication due to fluid dynamics. Everyone in the maternal-fetal system is terribly, terribly ill. My babies were severely discordant – one was half the size of

the other. And I weighed less 5 months pregnant than I did on my wedding day.

Around twenty-three weeks, we sought placental laser surgery at the International Institute for the Treatment of TTTS. Dr. Julian E. DeLia successfully performed the surgery, and everyone did very well. We hoped that both babies could hang on. Much to our horror and unrelated to the procedure I underwent, the smaller twin's heart stopped a few days after my surgery. One live twin, one dead twin, and so much pregnancy left. Now we had to wait.

Paul had to return to his job six hundred miles away. I planned to stay in Minnesota to give birth. Family would care for me, and Paul would return when he could. I got on the telephone in search of labor support. A friend introduced me to Kerry, and she agreed to serve as my doula. She listened to our tale patiently and sensitively. For the first few meetings, she simply listened. I had hope, I had sorrow, and I had no idea how to prepare for the birth of these two sisters.

Kerry's job was a difficult one. My body healed, but my heart was shattered. She supported my family's choices in finding help for both of our babies. She rejoiced with me over my survivor. She grieved with me over our deceased baby. Kerry included both babies in her conversations with me. She addressed my pregnancy just as it was. She never minimized our loss. I wrote a birth plan, and she helped me gently. She suggested coping measures appropriate for my fragile situation. She listened and listened. And then she took a deep breath, and told me something I didn't want to think about. She calmly and honestly told me that our deceased baby's appearance would be different than I expected. She would not be pale and smooth and perfect. I had never even thought about the changes in



Hodge family at the graveside, photo by Myra Toconita

appearance after a baby dies in utero. It didn't occur to me that I might not be able to see her face once I finally held her. I hated that.

A baby who dies before birth usually is born shortly after her demise. When an identical twin dies, the departed twin stays where she is while her sister continues to grow. For us, that was a period of thirteen weeks. I lay on my side, reading and crying, writing and waiting. Kerry visited periodically, phoned me, and waited.

Paul came up for a visit. I was nearing 36 weeks. We prepared a layette and a burial gown. We readied our toddler for yet another absence of both of his parents. Our ordeal — that started with a surprise pregnancy and home-birth plans, progressed to laser surgery, and brought us across the country — would be over soon. My labor began.

I am a doula. My labors are no different than those of the women I have served. This time around, it was swift, completely unmedicated, and bittersweet. As the contractions came, I held fast to what I have learned. I was not washed away on a tidal wave of panic, but there came a point where I could not muster the knowledge I needed. Kerry filled in the gap. She refocused me and told me I was in transition. She quietly spoke the words I needed to hear and wholly joined me on the way to birth. She redirected Paul so that he could help me better, and it was finally time to push.

Kerry's eyes shone as she placed my hand on the little wet head emerging. My anxiety melted away as the strength of beautiful birth unfolded. Faith Juliana Raphaela was born just after midnight. She stretched, cried, and nursed. Kerry helped me position my daughter and created some space for us in the crowded

OR as Paul and I held our baby with great wonder and relief.

Twenty minutes later, in complete silence, Grace Raphaela was stillborn. Those around us allowed Paul and me to react first. Grace's skin was grayish-green. Her eyes were closed, and her body was slightly flattened by her growing sister. She was cool to the touch. Her tiny hands and feet were lovely. We stroked her arms and legs and talked about how she looked to us. Our words came in sighs. It seemed like a lot of time



*Doula Kerry and baby Faith
photo by Myra Toconita*

passed. We could not say goodbye to this small girl whose life was so brief.

Faith, a premie, was taken to the Special Care Nursery, and Paul went with her. Once she was settled, he returned to dress Grace. Kerry stayed with us offering congratulation, consolation, and continuing her support. She told us how proud she was of us. She told us our girls were beautiful. She made us comfortable, and then she was gone. She would see us again soon. Grace was then taken to the morgue. I thought I would die.

When one of my twins died, so did my dreams of two pinkie-pies playing on a blanket, two milky smiles, two first everythings, two times mother of the bride. When my pregnancy continued with a loss, I needed constant, consistent support. Joy and sorrow wrangle and take turns even now. I cannot say that I have one baby. What I see is that I have not two babies. My joy is boundless that we have Faith. My sorrow is bottomless that Grace is not here. Having a doula who could competently and appropriately address my unique situation was invaluable. She conducted herself with compassion, expertise, and love. She supported my family and me, easing our transition to a life of loving Faith and missing Grace. Kerry was not afraid of our sorrow. She did not scold us for being sad; she didn't tell us we had to be strong for the living baby. She respected that emotions come when they come, and she encouraged us. It was important to us to have a person in our life that acknowledged both twins.

Doula care for a mother who loses a multiple is complicated, emotional, and essential. When life and death blur, special care is required. It takes an exceptional woman to care for an expectant, bereaved family. We found that woman in Kerry and will always be grateful.

Amy lives with her husband and their son and daughter in Kearney, Nebraska. She is a Certified Doula with DONA in private practice. She also is a speaker on doulas and twin loss. She is active in the Center for Loss In Multiple Births (CLIMB) as a member and contributing writer for their publications. She welcomes contact at amyfhodge@msn.com.

See a copy of Amy's birth plan on the next page.

**More information about doulas
and DONA can be found at
www.DONA.org**

Hodge Family Birth Plan

*Amy and Paul Hodge
Babies Faith and Grace
Kerry Dixon, doula*

Labor:

- § For hydration during early labor, I prefer to drink clear fluids rather than have an IV.
- § I'd like to use the shower and tub for pain management.
- § I'd like to be as mobile as possible while in labor.
- § Please do not offer me pain medication.
- § I ask my physician's assistance in avoiding episiotomy. We will apply warm compresses and oil, if possible.

Birth:

- § This was a Twin to Twin Transfusion Syndrome Pregnancy. We sought laser surgery to try to save both babies. One of our unborn twins passed away unexpectedly. Her name is Grace. Our surviving daughter's name is Faith.
- § We wish to spend time with both twins. We would like to see and hold our girls as they are born.
- § We can provide placental analysis protocols from the TTTS Foundation and wish to speak with our physician about analysis. We would also like information about autopsy for our deceased twin.
- § We have a gown for Grace to wear and a memory box in which we will keep whatever keepsakes are possible to have (footprints on card, lock of hair, photographs, etc.). Please assist us gently as we say hello and goodbye to our baby girl. Also, we have a casket for Grace. We will inform our undertaker as to when he can come to receive Grace's body.

Newborn Care:

- § We wish to waive eye prophylaxis for baby Faith and will sign the necessary forms.
- § Faith will be exclusively breastfed. Please do not give her supplements of any kind or a pacifier.
- § We prefer that our surviving baby stay with us in our room and seldom, if ever, spend any time in a nursery (health permitting, of course).

Unexpected situations:

- § If for any reason Amy and Faith need to be separated, Paul will accompany Faith while Kerry remains with Amy.
- § If a c-section is medically indicated, we request that all staff in the OR keep conversations about topics other than the birth to a bare minimum.