

MOST BABIES WHO COME INTO OUR NICUs stay for weeks or even months. But occasionally a baby will come to stay for only a few minutes, and those few minutes can make a lifelong impact on those involved.

On the morning I met Sue and Mike Reed, I already knew their baby's stay would be measured only by the minute hand on the clock. The couple had married in their early forties. Blessed with one healthy child, Samantha, they were inspired to try for another. After a few difficult starts, Sue found out she was pregnant in May of 2003, two months shy of her 44th birthday.

Because of Sue's age, her doctors scheduled her for amniocentesis, which revealed that the baby was a girl. At only 15 weeks gestation, Sue and Mike named their new daughter Gabriella Grace Reed, or "GiGi" for short.

But not all the test results were in yet, and only a week after the test, Sue woke with a feeling that something was "not OK." Later that afternoon, a phone call confirmed her suspicion. The doctor told Sue that she was 95 percent certain that GiGi had trisomy 18.

In an interview with me months after GiGi's birth, Sue recalled her reaction to the test results: "I struggled to hear more, even as I began shutting down." The "more" she was struggling to hear was that most women opt to terminate these pregnancies.

Mike and Sue spent the weekend asking, as Sue puts it, "the hard question of what God was doing here." During this difficult process, Sue couldn't help but recall an abortion she had in her youth. "It punctured my heart forever," she sobbed.

Much of the time mothers like Sue—with these punctured hearts—bring into our NICU a baby with a genetic anomaly known to them before delivery. And the question is whispered—"How could she have allowed this to happen? Surely she must have known."

We tend to think of the birth as a single event. But as Sue was teaching me, her decision to have this baby was much more than an event. It was a path that she'd walked her entire life.

"I knew I couldn't abort again. I knew in my heart-of-hearts that God made GiGi exactly the way she was supposed to be made. I know that the scripture says, 'Before I formed you in the womb, I knew you. Before you were born, I set you apart.' God was asking me to honor this life. She was our daughter with a bad diagnosis, but that was secondary. Nevertheless, the diagnosis was like an end to my pregnancy. With each doctor's visit, I was sure GiGi wouldn't have a heartbeat."

A "Moment" in the NICU

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But as GiGi's heart continued to beat, the doctors began anticipating her live birth. They asked Sue how she wanted to care for GiGi after she was born. Sue remembers the doctor asking, with tears in her eyes, "How do you want this to play out?"

Sue and Mike instructed the doctor not to resuscitate their infant, but instead to offer all possible comfort care. "We

just wanted to meet her and love her, to hold her and be with her. We wanted to meet and love our daughter as long as she was going to be with us."

The night before the birth, Sue wrote a letter to GiGi in which she explained how she saw her new daughter: "Some people only dream of angels, but I get to actually give birth to one and then hold her in my arms. I am so very blessed. See you tomorrow, Sweet Girl."

On February 5 at 10:00 AM, I entered labor and delivery to meet a couple who appeared like any other expectant parents carrying a video camera. But this video recorder would singularly record the two most sacred moments of life—birth and death—all on one tape.

One of the nurses handed me some scrubs, and I must have looked startled because she said, matter-of-factly, the birth plan calls for the chaplain at the delivery. "That's OK, isn't it, chaplain?" Mike asked. I agreed that it would be, and 20 minutes after Mike and I dressed in scrubs, GiGi emerged, looking like a perfect baby.

"I expected a deformed baby," Sue admitted, "but she was beautiful. It was like a visitor from heaven. It was like God showing me that what we did was the 'Faith Thing.' I remember feeling like my heart was exploding so joyfully. It was like seeing God on earth. It struck home that God hears, sees, and answers prayers. Even though I'd wished for a better outcome, I'm grateful that God chose us. I never thought I could walk through something like this."

It is often difficult to understand other viewpoints, to appreciate how other people view life-and-death decisions and the reasons behind those decisions—even how little medical considerations matter to them. But for Sue, the decision to hold this life, even for the moment, was the right one. "It has made me realize," she said, "that every moment in life is important, even if it was just 80 minutes. I packed a lot of parenthood into those 80 minutes."

Later Sue added, "Ever since this happened, I've been very aware that sometimes in life we only get a moment. GiGi's life was such a moment. So fleeting, but so precious."

Sue's comment echos the sentiment found on a trisomy 18 support website hosted by trisomy 18 parents: "Sometimes love is for a moment. Sometimes love is for a lifetime."

Sometimes a moment is a lifetime.”¹ The Trisomy 18 Foundation is a nonprofit organization whose mission is to provide support, research and advocacy programs, and services to meet the needs of families whose children are diagnosed with trisomy 18. The foundation sponsors the Trisomy 18 Support Online Community Program found at www.trisomy18support.org, whose goal is to provide immediate, free, Internet-based access to families seeking needed information and ongoing community support to cope with the challenges associated with a prenatal or neonatal trisomy 18 diagnosis for their child. The online community supports families with children who are yet to be born, newly born, deceased, and surviving at all ages. Since this program was launched online in November 2003, it has served over 150,000 visitors to the site, with approximately 10,000–12,000 more each month from literally all around the globe.

You can find pictures of GiGi, the Reed’s birth plan, and the letter Sue wrote to GiGi at <http://homepage.mac.com/reedsync/blogwavestudio/index.html>.

REFERENCE

1. Trisomy 18 Support—Families Caring for Families. 2003. Retrieved February 15, 2005, from <http://trisomy18support.org>.

About the Author

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