

Garrett's death was expected. His suffering was not.

"He's missing one of the chambers of his heart," the doctor said.

Serious cardiac and cerebral anomalies and Garrett's low birth weight eliminated the options of surgery or transplantation. The doctor explained to the baby's parents that newborns have a heart vessel called the PDA, which closes after birth. "When that valve closes in Garrett's heart," he said, "he will slip away."

"Why can't you ... ?"

"What if it isn't as bad as you think?"

"But isn't there something ... ?"

The parents' desperate questions poured out to the specialists involved in their son's case. In a world of miracle babies, it was difficult to hear that Garrett didn't qualify for one of those miracles. But as the doctors explained, heroics would only have put him through misery without changing the outcome. And misery was the last thing they wanted for their newborn son.

Comforting ... and Waiting

On the second day of his life, three-and-a-half-pound Garrett went home to live with his parents and four-year-old brother. His days were filled with eating, sleeping, diaper changes — and being held nearly twenty-four hours a day.

Garrett's Story

*by Nelda S.
Godfrey*

Aunts, uncles, grandparents, and cousins came to visit, to help, and to love the newest member of their family. Hours were filled with an attempt at normalcy, at buying preemie diapers and finding formula and nipples that worked. All the while, they quietly watched for signs that Garrett was slipping away.

A week passed. Then three. Then six.

Garrett gained a little weight; his color improved. He began reaching for the play rings in his crib and followed his brother around the room with his eyes. Hope flickered in family phone conversations: "Maybe he's stronger than the doctors thought," grandmas and cousins would say to one another. The doctors, however, never changed their message: Garrett wouldn't live much longer.

Knowing what was ahead was hard. Yet, Garrett was surrounded by caring and loving family and friends.

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The Unexpected

In the tenth week of his life — without warning — Garrett pitched his head back, cried, and gasped for breath. After fifteen interminable minutes, he lay limp and exhausted. When the parents first sought an explanation, the doctor was noncommittal. But after several more episodes, one witnessed by the home health nurse that the doctor then viewed on videotape, the nurse and doctor reached the same conclusion: Garrett was suffering from air hunger.

"Is that painful?" the parents asked.

"It's different from pain," the doctor answered.

"Maybe worse," added the nurse.

They suggested oral morphine to ease Garrett's pain.

The home health nurse explained the trade-offs between alertness and the sleepiness that can result from pain control and helped Garrett's parents work through the decision they soon reached — to try small doses of morphine and carefully guard the baby's responses. The episodes stopped soon after.

On the Saturday of Garrett's eleventh week, he stopped eating. By Monday he could no longer swallow. Again, his parents worried about his comfort, about his breathing, about keeping him free of pain, about the difficulties of administering morphine to him. The doctor suggested drops of morphine in the baby's cheek that would be absorbed into his system.

During a coughing spell that evening, Garrett spit out a large amount of the morphine. Shortly after, he began to moan. His mother feared that the drug had worn off and that Garrett might be in pain. Had they administered the drug incorrectly? Should they take Garrett to the hospital? Could they reach a doctor at that hour?

While Garrett's dad held him and played with his brother, his mother tried to call the doctor, only to find out that another doctor was covering for the regular pediatrician and a new nurse was taking home health calls. Frightened, she clicked off the questions in her mind: Which pharmacy has morphine suppositories? Would the neonatal specialist be the one to call? But he was three hours away.

Mercifully, Garrett's moans subsided. The home health nurse suggested a pharmacy, and the on-call doctor worked out a morphine dosage with the neonatal specialist miles away. The prescription was picked up and, after being given small amounts of morphine to keep him comfortable, Garrett slept calmly and quietly the rest of the night.

Twelve hours later, cradled in his mother's arms, Garrett quietly slipped away.

Power in Palliative Care

Real care at the end of life, just as real life itself, is infinitely complex.

Despite the drama of the baby's last forty-eight hours, Garrett's parents were pleased with the care they were able to give their baby. The medical community supported and encouraged their decision to bring Garrett home to die. The health care systems they encountered responded quickly and provided thorough information when crises arose.

Retrospectively, however, they wondered how it could have been better, how their last days with Garrett could have been smoother. Would more information in the beginning, more detailed knowledge about what to expect as Garrett's death drew near have prevented their panic and worry?

When family caretakers make a decision to provide comfort care to a loved one at home, fear of the unknown is one of the biggest challenges that they face. Information becomes power. Fear of the unknown is a huge challenge.

Knowing to whom to turn and in what circumstance provides caretakers with a sense of security and well being. Moreover, knowing *what* to expect, when possible, can help to eliminate traumatic moments, freeing the family to concentrate on the kind of comfort care they hope to provide.

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