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The “big girl” Who Shrunk into a Baby

Hans-Ulrich Bender, MD

IT WAS OUR fourth or fifth time sitting down together with E.’s parents. E. was five weeks old, and she had endured a difficult start. Her mother’s uterus had ruptured and E. suffered severe asphyxia and brain damage. She arrived by helicopter from her small hometown high in the Swiss Alps to the children’s hospital, where weeks of hopes and fears on the neonatal intensive care unit (NICU) began. As time passed, she grew more and more stable, her epilepsy calmed and she even managed to drink by herself, although very little. The conversations with E.’s parents were intense and deep, discussions about parenting, life, death, hope, despair, and uncertainty.

That day’s goal was to talk about discharge from hospital and taking E. home. Her mother was happy, her dad was nervous, and the two siblings could not wait for the little sister to finally come home. In the middle of discussions of what-to-do-ifs, E.’s father all of a sudden said, “It’s funny how she changed her size and grew small again—to a baby.” Silence. Then he explained to the curiously smiling eyes of his wife and me: “It’s like she was a big girl, when she was first-born, when she was so sick, when we didn’t know if she would live or die. We gave her all the power; for us, she was the one who decided after extubation if she would live or not. She was such a big girl, we trusted her that she would make the right decision for all of us. I literally regarded her almost as bigger than me.” E.’s mother smiled gently. “And now?” he continued, “She got better—and it is as if she shrunk, she is a little baby again, she is small, a normal baby size.” He gestured his hands to show the sizes of his “big” and “small” baby and I believed I saw a tear in his eye. “Now I am the one who has to decide for her, who gets up at night, who changes

the diapers. She’s now almost like a normal baby. It’s wonderful.” He paused, overwhelmed by the perspective of taking his baby girl home. “And I am worried,” he added.

Our conversation shifted to talking about how to observe a baby to tell whether she is well or not—in light of all that had happened before and the burden of responsibility and uncertainty going forward. How they needed to establish trust in their parenting hearts and eyes, again. I assured them that the pediatric palliative care team would keep close contact with the family after discharge, which I explained is a core component of our service. They were clearly relieved to hear this, and by the end of the session the room had returned, mostly, to joy.

Effective communication with parents when the life of their child is threatened has an enormous impact. Sometimes parents’ distress may translate into a perceived change in physical size of someone—in this case their child. This little story is offered as an illustration of a transformation experienced by a father as he interpreted a change in size of his baby girl. At the same time, it illustrates the need for support and security that parents may have when their baby is discharged home from hospital after a critical or extended time.

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