



The Final Chapter

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Julia was a six-year-old girl with stage IV neuroblastoma for which she had received two years of aggressive multimodal therapy. She lived in a small town about three hours away from the children's hospital where she was treated. Her parents were both teachers and she had two younger sisters, Jessica, 4, and Jemima, 3. Julia's parents alternated taking leave from work and staying with her in the hospital. While one parent was with her, the other parent would go home to work and care for her sisters with the support of their extended family and community, particularly people from their church and the school where they both taught. Julia was one of my first primary patients as a new pediatric oncology nurse.

It was late September when Julia's parents were told by her oncologist that her disease was so extensive and refractory that no further curative treatment options could be offered. I was with them in that meeting—and it was to me that her dad turned and said with anguish in his voice, “So *NOW* what can you do for us?” Responding to that question was my challenge over the weeks that followed. Pediatric hospice care was not available in Julia's town and, in any case, Julia and her parents were comfortable in the hospital with the staff that knew and loved them. So, it was decided that she would stay with us to die.

Julia's abdominal tumor grew so large that I was surprised it didn't split her tiny body open; she gasped for breath as disease invaded her lungs and became partially paralyzed and incontinent as her tumor compressed her spinal cord. The pain of her bony metastases was so severe that she stopped requesting to have me gently rub her legs and began requesting to have me simply blow on them because that was as much touch

as she could tolerate without increased pain. I spent hours just blowing on her legs when that seemed to bring her more comfort than all the fentanyl I could give. Much of her care focused on intricate pain and symptom management, in which the nurses and physicians and child life specialists collaborated with all the expertise each of us had to offer. However, I think the best nursing care I gave was just being there with her and her family as they faced her death.

After the meeting with her oncologist, Julia's parents turned to me for guidance in telling Julia that she was dying. Being teachers, they knew that there were numerous books to facilitate talking with children about death. And, because bedtime story reading was an important family ritual for them, they decided that this was the approach they wanted to take. I brought them a selection of such books that our unit kept as a resource for families and together we chose one, *The Fall of Freddie the Leaf: A Story of Life for All Ages* (Buscaglia, 1982). Reading a bedtime story was part of my evening routine of caring for Julia, so they asked me if I would read *Freddie* to her while they spent some time alone together. They planned on their return to then open the conversation about her impending death by asking her about what book I had read to her that night. I read her *Freddie* and, when I had fin-

ished, she looked up at me and said, “I think you should read this book to my mom and dad, too. I'm going to die, but I'm not sure how to talk to them about it. Maybe this book would help.” Her parents arrived back from dinner at this well-timed moment and the four of us had a long conversation.

Julia's mother was pregnant and due in early November and Julia's greatest sadness was when we told her it was very unlikely she would live to see the baby. She was absolutely certain that it was going to be a boy “because God wouldn't send them a girl right away to replace me,” and she made them promise that he would be named Kristian after her middle name, which was Kristine.

Julia was also distressed that it was unlikely she would live to Halloween, a holiday she loved celebrating in the hospital and for which she already had her costume ready—an elaborate pink and purple fairy princess dress with huge gauzy wings. So, the following Saturday, I arranged for us to close off the hospital playroom, all the on-duty and many of the off-duty staff came in costume, and we had a Halloween party for Julia. She was only able to attend for about 10 minutes and had to be wheeled in laying flat on her bed because her pain was too severe for her to sit up, but, with the help of many, many fentanyl boluses, her mom and I had dressed her in her costume, including the huge wings, and our fairy princess had her Halloween party.

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