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 intracranial 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 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 finished, 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.

Catherine Fiona MacPherson, RN, PhD, CPON®, is a staff nurse in the Seattle Cancer Care Alliance Inpatient Unit at Seattle Children’s Hospital and a clinical assistant professor of family and child nursing in the School of Nursing at the University of Washington in Seattle. The author takes full responsibility for the content of the article. No financial relationships relevant to the content of this article have been disclosed by the author or editorial staff. MacPherson can be reached at catherine.macpherson@seattlechildrens.org, with copy to editor at CJONEditor@ons.org.

Digital Object Identifier: 10.1188/12.CJON.E190-E191
After naming her unborn brother and having her Halloween party, it seemed as if Julia was done with living and ready to prepare for her death. Julia decided that she wanted to tell her sisters she was dying and asked if I would read *Freddie* to them as well as the way of telling them. She planned every detail of how the reading would go, including that her sisters had to wear pajamas and have popcorn to eat because that was what they did for bedtime stories at home. The next night, her grandparents brought her sisters to visit and the three of us snuggled up in the hospital bed. Jessica was on one side of me and Jemima on the other, both in pajamas eating popcorn, and Julia with all her lines and tubes and drains placed very carefully in my lap and using what little strength she had to try to help me turn the pages. Her parents videotaped what would be the last bedtime story for their three girls.

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.

Julia spent one evening with me and her parents dictating a list of which of her toys and clothes were to go to which of her sisters; and talking about how she wanted her bedroom at home to be redecorated as a “family room where everyone can go to hang out and watch TV and play games and read books and remember me.” And she sought assurances from her parents that photographs of her would still be displayed in the house and even offered opinions on which ones, saying that she wanted “some from before when I was cute and had hair but also some from after so nobody forgets I died of cancer.”

On another evening, I guided Julia and her parents through planning her memorial service. Her parents wanted a traditional funeral to be held in their little old church with a reception on the lawn afterward. It fell to me to explain to Julia in general terms what a funeral involved, and to ask her if there was anything she especially wanted to happen at it. Being Julia, of course she had opinions! She wanted “pink and purple flowers ONLY,” and little kid chairs and tables at the reception with lemonade and peanut butter cookies. Most emphatically, she insisted that she wanted to have an open casket and wear her fairy princess costume, including the wings. We tried to explain what a casket looked like and that there would not be room for her huge wings—at which point she burst into tears and told us that she needed them and that she wasn’t going to make do with just any wings when she got to Heaven, she wanted her own wings to go with her. Her ultimate request for her funeral was that, in addition to the eulogy, there be a children’s story time such as what took place at Sunday services in her church when all the kids would come sit on the steps in front of the altar and listen to a story just for them. And, no surprise, what she wanted was for me to read *Freddie* “upside down,” she said, “like the librarian at story-time, so everybody can see the pictures. You better start practicing with me.”

Julia died at sunrise one day in mid-October, with both her parents and myself at her bedside. They held her, and I stood with my arms around both of them. When the staff from the funeral home arrived to collect her body, I slipped her into the body bag and, with tears pouring down my face, taped her wings to the outside of it while her parents smiled through their tears. Many of my colleagues drove to her small town to attend her funeral several days later. The little old church was packed with the crowd overflowing onto the lawn outside, but her parents had set aside a section for her nurses as guests of honor at the very front of the church beside the family. The funeral was just as she and her parents had planned it. There were masses of pink and purple flowers just as her obituary notice had requested, she was dressed in full fairy princess splendor, and her wings were carefully folded into the side of her casket. I tearfully read *Freddie* sitting on the church steps in front of the altar surrounded by almost a hundred kids of the community—her sisters, relatives, friends, neighbors, and many kids her parents had taught. It was a perfect autumn day of blue skies and vividly colored falling leaves incredibly suitable for reading the story of a little Freddie the Leaf learning the seasons of life.

At one point, another leaf in the story says to Freddie, “Everything dies. No matter how big or small, how weak or strong. We first learn to do our job. We experience the sun and the moon, the wind and the rain. We learn to dance and to laugh. Then we die” (Buscaglia, 1982, p. 16). Since reading *Freddie* for Julia, I have read the story again many, many times with other kids and families and each time those lines remind me of Julia and of what I have learned from her and all the other kids who make it such a privilege to be a pediatric oncology nurse.

*Note. All names and identifying details were altered to protect patient and family privacy.*

**Reference**