

Day." Everything came so hard for Avi—sleeping, eating, talking, voiding—that every one of life's simple achievements was special and significant.

Still, there was never a question in our minds as to whether or not to fight for Avi's life. When our third child, Max, was born—Avi was four by then—we hoped that his bone marrow might be suitable for the operation. It wasn't, but Marc and I refused to give up.

A Sudden Illness

A few weeks short of his fifth birthday, Avi suddenly and mysteriously became very sick. What we didn't learn until later was that he was suffering from a brain tumor. We rushed him to a local hospital. Still barely the size of an 18-month-old, he was very weak and dehydrated from vomiting. The doctors asked us again and again, "Does he talk? Does he walk? Does he have a personality?" I wanted to bring in a videotape and show them just how much of a personality he had. I wanted them to know that Avi was a child worth saving.

Eight hours or so after he arrived in the hospital, Avi began to have trouble breathing. His eyes were frightened. Marc and I fell back on a family tradition; whenever Avi was about to undergo an unpleasant procedure, we asked him to smile. It distracted him from his pain and fear. Marc said, "Avi, smile." And he did. It was the last time we saw his precious smile.

A few weeks after Avi died, I received a telephone call from a wonderful woman named Maggie who had been a monitor on his school bus. She recalled how he always spent those long rides singing and laughing. Until she met Avi, she said, she had always thought of herself as a lowly, ill-paid bus monitor. But Avi, she said, made her realize how much love she was capable of giving, and getting. She told me, "I love what I do, and I'm never going to apologize for it again."

Avi wasn't forgotten by his friends, either. About

a year after he died, we heard that Brian, one of Avi's close friends at school, was talking to one of the school's administrators. "Do you want to see my pictures?" Brian asked. He then pulled out a photo of himself with his arm around Avi. "That's my best friend, Avi," he said. "I used to help him do puzzles. I sleep with his picture under my pillow every night."

Avi's Legacy

I know for a fact that living with Avi gave our family a genuine empathy for other people, with or without disabilities. Rebecca in particular seems to have learned compassion at an early age. Not that she's selfless—she has the normal egocentricity of a four-year-old—but I don't think it's a coincidence that she is the one in her class who always comforts the other children when they're crying.

I still sit up in bed many mornings, hoping to hear the sound of Avi running to our room and see him climbing into our bed, saying, "Hi, Mommy! Hi, Daddy!" Marc and I now know that there's nothing harder in the world than losing a child. But we also realize what a great gift we were given for almost five years. Because Avi insisted on taking such pleasure in life despite all his medical problems, we now understand that, as parents and as human beings, we can take almost nothing for granted. What we can do, however, is appreciate the miracle of our children.

At his funeral, we asked family members to eulogize Avi. I remember my mother mentioning not only how much we were all enriched by having him in our lives but also how he "sang with a sweet voice right on pitch and could tinker with a tape machine as well as any disc jockey."

Afterward, at the cemetery, we wound up Avi's favorite music box and placed it on top of his small coffin as it was lowered into the ground. As we all took turns shoveling dirt into the grave, the music played sweetly, on and on, until it was finally stilled.