

A Caregiver's perspective

"My son is alive!"

Dixie Fremont-Smith Coskie, an advocate for children and the disabled, writes about the challenge of caregiving from a mother's perspective.

As I started emptying the dishwasher, I suddenly wondered whether I'd ever actually turned the darned thing on. I was so tired I couldn't be sure, but since the plastics felt warm, I guessed I had.

In the month since my son Paul had his bone marrow transplant, life had been hard. We—my husband, our seven other children, and I—had tried not to expose Paul to germs. We were constantly washing our hands. Although he was 17, Paul's immune system, temporarily weakened by chemotherapy drugs, was as undeveloped as that of a newborn.

Now, Paul spent his days in his bedroom. A window allowed stale indoor air to flow out. He was plagued by the side effects of his treatment: Dizziness. Headaches. Loneliness. The snow outside was white, the atmosphere cold. Life moved slowly, heavily.

A second blow

I thought back to the rehabilitation hospital, where four years earlier Paul had lain in a coma after being hit by a speeding car. After his eyes finally opened, he had to relearn to walk, talk, and perform the basic tasks of living. Paul had fought hard to heal and eventually did things once deemed impossible by his doctors.

And then, the blade had twisted again. Paul was diagnosed with chronic myelogenous leukemia (CML), a rare, life-threatening cancer that starts in the bone marrow. It was excruciating to wait to find out whether one of Paul's siblings could be a donor for a bone marrow transplant. Without a perfect match, Paul's chances of surviving were small.

During those dark days, I questioned

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whether there was an afterlife. Looking for answers, I began to pray. Faith had sustained my family and me in the past, and I hoped it would again. Thankfully, Paul's 11-year-old brother, Kevin, was a match and was able to give some of his marrow to help save his brother's life.

Caregiving ... and giving ...

Since Paul's transplant, the rest of the kids had been taking turns getting sick.

Today, a stomach bug had hit with a vengeance. Heaving sounds could be heard throughout the house. I was so tired of the commotion, the crying, and the caregiving ... and giving. Now my 13-year-old daughter, Monica, was screaming for a bucket. I needed to reach her before she threw up.

The fantasy of other lives was playing distantly on television. A woman was laughing and swimming. Her husband embraced her as their children frolicked in the sand and the waves. I wanted to throw the bucket I was holding—to smash the TV, break the façade.

I changed my baby son's diaper. The sight of diarrhea triggered a new wave of exhaustion. Little Jack began to cry, and I hugged him close. We both cried.

Then, as I mechanically began to clean up the mess, I saw Paul's face in my mind's eye, and it dawned on me that as a result of his injury and illness, our family had been startled from a kind of slumber. We had awakened to a different life, a life that really is a gift, and a fragile gift at that.

I stopped crying. Suddenly I knew I would be okay. We would all be okay. We would survive.

Today, Paul James Coskie is cancer-free. 