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The gift is life

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"He's in serious trouble—someone better talk to the mother about it," said the nurse, as I approached the patient's room. As the attending physician, I was the designated "someone" who had to tell a mother that she would be taking her teenage son home to die.

I paused in the hallway to review the patient's chart. The boy had a neuro-metabolic degenerative disease. He had gradually lost physical strength and coordination to the point of requiring assistance with simple daily activities. He had been admitted many times in the past year for dehydration, pneumonia, and seizures. He was the youngest child of a poor, small, frail woman who had tried to care for him at home despite her recent surgery. While attempting to reposition him in bed, her surgical sutures had split open and she was forced to bring him to the hospital. The boy had a severe infection that caused multiorgan failure. His health deteriorated rapidly despite modern medical treatment. From this point on, there would be more caring than curing.

It was a sunny fall day, but the room was dark and quiet. The mother had pulled the shades down, hoping her son would get a few more moments of rest.

"Good morning, Ma'am," I said softly. She looked up slowly, and a weary gaze searched my face for answers to her unspoken questions. She seemed detached as we discussed his treatment. She had previously indicated she wanted to take her son home to his family and friends, so her question was not entirely unexpected.

"Dr. D, when can I take him home?"

"Let me talk to the hospice folks, and make sure they know how things stand," I replied. Because of the severe deterioration in the boy's health, his pediatrician had set up hospice care several weeks prior to admission. "I think we should be able to have him home by tomorrow; I'll check with the staff regarding transportation."

"How much time does he have?" The question was simple, the answer critical.

"He cannot tolerate feeds, and his body is too weak to fight off infections. We may lose him if he does not come around in the next couple of days. Even if he does, the next setback would be more than he can handle." She nodded as I spoke, indicating that her worst fears were being confirmed. After a pause that was bursting with a lifetime of memories and emotions, she voiced her acceptance of the inevitable.

"We'll be OK. I've been through this before." She was referring to her daughter, who had been my patient for years. Her voice cracked on the last phrase. Her eyes were moist with unshed tears. I sensed that she needed both privacy and a companion.

"I know you have, and just like the last time, I'll be here if you need my help." We talked for a few minutes. I promised to stop by later that day. She acknowledged my support and expressed her gratitude with a hug. As I was leaving the room, my mind raced back to the time I had been unsuccessful in mediating a conflict between the mother and her teenage daughter.

"Dr. D, please talk to her. She wants to go have a baby. You know she can't take care of herself. What will she do if she gets pregnant?" I agreed with the mother's viewpoint, primarily from a medical perspective. The teenager was the index case of the familial degenerative disease. The inexorable progression of the disease had taken its toll over time. The stress of pregnancy could lead to severe and possibly irreversible consequences. I asked the mother to wait in an adjoining room and interviewed the daughter separately.

As I closed the exam room door, the daughter sat up in her chair. She looked weaker than on the last visit. Her eyes, however, flashed defiance, and she had her jaw set. As far as she was concerned, her mother was being unreasonable in sharing their private life with the doctor. I sat down and told her that I wanted to hear her side of the story. In no time at all, she let down her guard. I saw a frightened girl who surprised me by the scope of her life planning.

"I know I'll get sicker when I get older. I just want someone to love and care for, someone who will take care of me and my mother when I cannot do it." In her own way, the daughter was trying to leave a legacy and ease the mother's burden at the same time. I was touched by her innocence. When I explained how difficult it would be for her to go through a pregnancy, she did not hesitate to inform me that it would not get any easier if she waited. She was right about that, and I struggled to come up with an alternative that would give her an affectionate companion without compromising her health.

"How about starting with a puppy instead? No diapers, no sleepless nights, and you can get all the snuggles you want." She gave me an amused smile, and I pressed on. "Besides, you won't have to come to the hospital to get one, and I know you like to stay away from hospitals." She promised to think about it. I thought I had done a good job of crisis intervention when both mother and daughter thanked me as they left the clinic together. A few months later, I found out that my mediation had not been as successful as I had hoped.

The daughter wasted no time in getting pregnant. She delivered prematurely at home and the baby was admitted to the neonatal ICU for several weeks. Meanwhile, the daughter took a turn for the worse, had a series of strokes, and could not feed or care for herself, let alone her new baby. During that time, I talked to the mother many times each month, trying to help one of her wards get started in life and keep the other from losing it. Within 6 months of delivering the baby, the daughter succumbed to complications of a large stroke. The usually stoic mother had gone through a difficult time coming to terms with her daughter's premature demise. Now the mother

was going through the grieving process a second time.

The boy went home the next day. About a week later he died quietly at home. After talking with the hospice staff, I called the mother. Her strained, hoarse voice had a flat tone. I knew she had shed many tears since our last conversation. I asked if the boy had been comfortable in his final days. She said he was, and added that she was glad he had died at home with his family rather than at the hospital. We talked about shared memories of small victories and big losses. When I asked about the baby, her voice brightened noticeably.

"Oh, he's tearing up the place. He's something else." She recounted his progress and how well he was doing. "You should see him. He's just like his mother." She was able to see her daughter in the baby's smile, and remembered how her son had adored his little nephew. She recalled how they had played and laughed together. She knew the baby would keep her busy for a long time, and expressed hope that he would do well in the long run. Her grandson was becoming the new focus of her life. In his own way, the baby was showing her a way of connecting a difficult past with a promising future. The baby would keep the family engaged and involved in life in ways a puppy never could have.

I realized then that by not following my well-meaning advice, the daughter helped her mother live through the loss of a child with the gift of a child. The disease took her life, but her spirit brought forth new life. And in so doing, she taught me that the most precious gift in life is the gift of life.



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