
ESSAYS/PERSONAL REFLECTIONS

The after effects of a mother's loss

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It has been almost 16 years since my son's death from leukemia and complications following a complex stem cell transplantation. There is not a day that goes by that I do not think, dream, or do something meaningful to honor David's short-lived life. David was diagnosed at the age of 10, in remission for 3½ years, and suddenly relapsed just before entering his first year of high school. His relapse left us heart-broken and with a sense of how unfair life could be. David felt betrayed and devastated, but as a family we stood united and faced whatever came our way. Unfortunately, this does not have a happy ending. David died just shy of his 16th birthday on August 2, 2000, from a multisystem organ failure following a lethal fungal infection while immunosuppressed.

Several weeks after his death, it was my mother's 75th birthday. Although I was in no mood to celebrate, my mother was in declining health, and I was keenly aware that this could be her last celebration with us. Our family went for a Sunday brunch at a restaurant on the water on a beautiful sunny day. All was going well until I heard a sound that sent shockwaves through my body. It was a crying infant. To me, that high-pitched cry sounded like the scratching of nails on a chalkboard. Prior to David's death, I wouldn't have thought twice about a crying baby, other than wanting to console it, but as the volume of the wailing increased, I began to feel a sense of panic and a feeling of needing to escape the baby's cry. I had never experienced such an uncontrollable urge before—even when David was at his sickest. My husband, daughter, and I worked as a team in dealing with whatever David's needs were, and we were totally attuned to how to help each other. This baby's piercing cry, though, was like a knife tearing through my heart. With each second that passed, I

felt a sense of rising panic and an increasing need to flee from the environment that was causing me so much pain. I bolted out of the restaurant, leaving my mother, father, brothers, and their families dumbfounded by my sudden departure.

Over the years since David's death, I have become committed to honoring his memory. My husband and I established a family foundation in 2006, a nonprofit 501(c)(3) organization with the primary purpose of educating nurses on how to help pediatric patients and their families through their struggle with cancer as nurses are the ones monitoring the patient's care 24 hours a day. Since his death, I came to realize that the psychosocial components of David's care (especially since his relapse) were not a primary focus within the complex medical care he was receiving, following a state-of-the-art stem cell transplant.

We were unable to locate a perfectly matched donor. Sarah, our 10-year-old daughter, was a near match and the only possible donor for her brother. Because she was not a perfect donor match, David was at high risk of developing complications from graft-versus-host disease (GvHD), where the donated tissue (graft) recognizes that it is in a foreign body (host) and attacks it. David was the first recipient of a new procedure that would reduce the risk of GvHD, called a T-cell depletion. Sarah's stem cells would be manipulated so that the chance of GvHD would be minimized. This was our only hope for David's survival—he was too weak from prior chemotherapy to endure another two years of treatment. We were in uncharted waters. David was the first recipient of this high-tech procedure, so no one really knew what to expect post-transplant. Each day was an ordeal. There were many moments of despair at first, as we watched the doctors and nurses immersed in his medical care. Whenever possible, in order to neutralize the intensity of each situation, David would inject his incredible sense of timing and humor to defuse the anguish of the many situations he was bombarded with. This was how we, as a family,

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were able to get through such an intense, horrendous journey. Through humor, we all endured.

Several years after David's death, I often wondered about the long-term emotional impact a family faces after losing a child following a transplant. I was well aware that most couples' marriages did not survive the emotional turmoil they have to endure through many years of treatment. My husband and I were the lucky ones, though. We worked very hard at "balancing on the tightrope" of caring for a child undergoing a life-threatening transplant.

Since his death, every month prior to what would have been David's birthday, on all major holidays, and especially on the anniversary of his death, my husband and I found ourselves depressed and out of sync. Finally, after several years of struggling with this, together, we realized and acknowledged that we were experiencing our own sort of posttraumatic stress event.

Approaching my 60th birthday, I began experiencing a few physical issues that concerned me. My primary care physician ordered many tests, including several MRIs of my spinal column. I'd had MRIs before, but always with my head protruding from the machine. I quickly dismissed too much thought about the test and pushed away my fears. I went alone to the hospital for the test. While waiting to be called, I filled out the necessary forms for the procedure. One of the many questions included was if I was prone to claustrophobia. I checked off that I was not. I had never had an issue with being in tight places. The technician called me in, I changed into a gown, and soon I was walking through the MRI's central operations station, where the technicians and doctors sat and watched as the images were transmitted onto computer screens. The station was dimly lit, there were no windows, the doors into the MRI room were several feet thick, and, in a matter of a few seconds, I felt myself beginning to get uneasy. Slowly, memories of David and his stem cell transplant came to mind. I was remembering the day he received full-body irradiation to eradicate his immune system in preparation for the transplant. The sounds, the flashing lights, and the thick, heavy protective doors all came back to me within a split second. As I walked into the MRI room, I saw the long tube of the MRI that my body would be going through. I knew the procedure was painless, but my emotions were starting to get the best of me. I climbed onto the platform, and the two technicians made sure I was as comfortable as possible. I had asked them to cover my eyes and requested earplugs to mask the noise. I was wrapped in a blanket and ready to go into "the tunnel." I was as ready as I could be until I heard a "click." It was a cage to hold my head in place and to get pictures of my upper spine. The technicians

had not warned me of this. Suddenly, my head was encapsulated and I yelled out loud, "WAIT! WAIT! WAIT! You didn't tell me anything about my head being in a cage!"

As I said those words, I was immediately brought back to a memory of David undergoing a full-body MRI 20 years earlier, before he was actually diagnosed with leukemia. When he saw the huge machine and was told what would happen, he was terrified. He was so panic-stricken by the environment, he too had yelled out, "WAIT! WAIT! WAIT!" and had the technicians tell him everything that would happen before he would go in the machine. David was 10 years old at the time and always required a full explanation of anything new he was to experience. I had always considered him cautious and a bit clingy in the past. The only way David would allow the doctors and technicians to perform the MRI was if I was in the room with him holding his ankle, which, of course, I did.

Fast forward 20 years. I now recognized that I was facing the fear and anxiety that David may have experienced. I was no longer a nurse, a wife, a mother, or even an adult—I felt like a child, terrified, panic-stricken, and unable to take control of my emotions. The experience was also coupled with a sense of guilt and shame that I felt for not being more aware of David's experience when it was happening to him those years ago.

As I went, head first, into the tunnel of the MRI, I found myself trying with all my might to bring myself into that calm, relaxed, safe place that meditation can bring. I tried to envision walking through the woods with my dogs, smelling the fresh air after a rain, and the glitter of sunshine shimmering off the wet leaves. All I was aware of, though, was my heart pounding and my body perspiring profusely. My mind went to scenes of horror show—of being buried alive in a coffin and with each breath thinking it would be my last. I would suffocate and die. My mind then shifted to thoughts of feeling nauseated. I began to fear the thought of being unable to turn to my side to vomit and that I would aspirate my own stomach contents. It took all my might not to panic and scream. Suddenly, the technician notified me that the first part of a two-part series was over, and they brought me out of the MRI for readjustments for the next study. Once out of the machine, I bolted upright and started to cry, uncontrollably. I told the young technician that I was having a panic attack and could not continue with the next part of the test. She seemed perplexed and confused as to why this was happening to me. I explained the loss of my son and how the MRI brought back vivid memories of when he was ill. I asked if a nursing colleague of mine, who worked in the hospital, could be

contacted to come be with me. My friend soon arrived and immediately noticed how distraught I was and spent considerable time consoling me. Once I was calmed down, I contacted my husband to come pick me up (in retrospect, I should have had him accompany me to the test), and he arrived within minutes. We met at the hospital entrance. He wanted to take me into his arms and hug me, but I didn't want to emotionally unravel in public. I pulled him into an empty conference room and began to cry again. I told him what happened, and we relived our memories of our son and talked about why I had experienced the panic attack.

It has been two months since that experience, and I still have not fully recovered. While I was watching a rerun of the acclaimed television show "Grey's Anatomy," there was a scene of a patient undergoing open-heart surgery without general anesthesia; he was so allergic to it that the team decided to do an epidural instead. He requested to be fully awake for the operation. Slowly, he became aware that he could smell and hear what was happening to him. He was cognizant that there were many eyes on him, not only from the operating room personnel, but onlookers, from overhead, peering down on him from an observation room. His eyes began to dart back and forth, his respirations began to increase dramatically, as he was trying to comprehend what was happening to his body. Then you see it. You see the patient begin his descent into chaos . . . fear . . . and then, a full-blown panic attack. As I watched this scene from

the comfort of my own home, I felt as if I too were being pulled into his experience. I felt my heart pounding and my respiration increasing. I immediately shut off the television.

Do parents of children who have undergone an unsuccessful bone marrow or stem cell transplant experience posttraumatic stress? My personal answer, without hesitation: Yes! Any major celebrations, especially holidays and birthdays, are met with a heavy heart, trouble sleeping, moodiness, and a sense of doom. The anniversary of a child's death is particularly difficult. Each year that goes by signifies another year of a family's magnitude of loss and the unfulfilled dream of watching their child grow up to become an adult and start their own family.

There is an obvious opportunity, in my opinion, for recognition, promotion, and implementation of advanced education for nurses, and for other health-care professionals caring for a child and their families, during and following the illness, and most especially after the loss of a child. For us, it has been 16 years since losing David, but I would be willing to predict that, regardless of the time gone by, for "orphaned" parents, healing from the a loss of a child is an ongoing, sorrowful process.

Although physically gone, my son is always in my heart. His memory propels me to honor him with the work that our family foundation does to keep his memory alive. It is all part of the continual healing process.