

Life-Threatening Illness and a Mother's Emotional Journey: Lessons in Care

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WHEN MY SON, DAVID, was 10 years old in 1995, he was diagnosed with a life-threatening illness—acute lymphoblastic leukemia. Over the next five years, the entire medical team, David and our family, were busy trying to defeat the illness and spare his life. Every ground-breaking procedure was provided, but to no avail. He lost his battle in 2000.

It has been 16 years since his death and I am still haunted by specific memories, especially during his last three months of care after a high-risk stem cell transplant. His medical care was clearly delineated but there were other aspects that were unaddressed, especially during those life-altering, roller coaster ups and downs of chemotherapy and transplantation. The loss of my son changed me forever. I see life differently. Over the years, I have been motivated by my love for David and the need to honor his memory. This has been a long and arduous journey, but I have recognized that there are distinct areas of care that have to be addressed when a life-threatening illness strikes. The purpose of this article is to reveal my journey, as a nurse and mother, what I have learned, and to offer specific recommendations for healthcare practice.

My husband and I established a family foundation in 2006, to honor David's memory. There is no way to describe our deep sense of loss and our vivid, anguishing memories of what David had to endure, even now. Soon after his death, we decided as a family to move away from our home, in the United States, to London. Staying in our home town was torturous for us all—the memories, dealing with friends and family, and the overall reminders of the entire experience were just too painful to deal with on an everyday basis. There was a job opportunity for my husband, Joe, in the United Kingdom. Our daughter, Sarah, had lived in the shadow of David's illness since she was five years old. After David's death and at the age of 11, she started a new school in London, struggled with a difficult mid-year transition, the adjustment to being an only child, and deeply mourned the loss of her brother and her best friend. We all needed to heal on our own terms and at our own pace. It took us several years to do this, but we endured as a family.

Lesson Number 1

It was in London, two years after David's death, that I became involved with an organization called the Teenage

Cancer Trust (TCT). They raised money and built inpatient centers specifically for teens with cancer. This was a new concept that I was unfamiliar with, and I decided that I wanted to get involved to learn more about the work they did. Soon I was attending monthly meetings at the main headquarters, in central London, with my goal to help parents whose teens were recently diagnosed with cancer, with suggestions on how to get through the first month after their child's diagnosis. From our own experience, the first month was an utter nightmare—your child and your family are overwhelmed with the diagnosis, the complexity of the treatment, and the unspoken fear of possible death. I decided I would help TCT prepare a brochure on suggestion tips for parents on how to cope with the magnitude of their child's illness that first month after diagnosis.

At TCT, I met other parents who had lost their teens to cancer and also wanted to contribute to helping others undergoing what they had struggled through. It was a nurse counselor, who specifically worked with dying teens at the Middlesex Hospital's TCT unit, who took me under her healing wings and helped me through the transition from the feeling of loss to the strength to heal. A deep friendship and respect soon ensued between us and TCT realized that we worked very well together—the nurse from the United States who had lost her teenage son to cancer and the nurse from the United Kingdom who helped to rebuild her life. They soon asked us to collaborate and present at The International Conference on Adolescent Oncology at the Royal College of Physicians in London. We both saw this as an incredible opportunity to educate healthcare providers on the needs of teenagers with cancer and to highlight how distinctly different adolescent cancer care was from pediatric or adult care. Our presentation took more than nine months to prepare. We met monthly and compiled universal challenges that many parents faced, which included the best of care and some major flaws in adolescent oncology. I presented the parents' perspective with what our family went through in the American health system, and my British colleague responded with her suggestions on how to improve care. It told a personal story that captured the attention of all who attended. It was an empowering experience to share my story. Most importantly, it gave me—a mother, a nurse, and a wife—a voice that was rarely heard. I knew that I needed to do something significant that would allow me to honor David.

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Lesson Number 2

After David had relapsed and required a stem cell transplant, I became aware that there was little attention given to the psychological aspects of care—for our son or ourselves. At that time, there was only one child psychiatrist assigned to the pediatric oncology department and his Freudian technique of therapy was not appropriate for our son or his present predicament. After David had his transplant, he was in strict isolation and in a private room for 28 days while his new immune system was developing. Anyone who went into his room had to undergo intense hand-washing technique, was gowned, gloved, and masked. Healthcare providers entered his room only when necessary and it had a profound effect on David's state of mind. He became atypically confrontational, angry, and aggressive. Members of his healthcare team assumed it was because he was in strict isolation, but my husband and I knew it was much more. From my past nursing education, I instinctively sensed that David had questions about his own mortality. He would not share these feelings with my husband or me, as he probably wanted to shield us from additional worry. As mentioned before, David, after three sessions with the child psychiatrist, decided he did not want to continue the therapy. We asked nurses and doctors to sit with David, but no one felt comfortable doing so. Finally, we pleaded with David's favorite transplant doctor to have the "conversation." It was obvious that the doctor was reluctant to have such a difficult encounter, but he really had no choice. Three hours later, the doctor emerged from the room, exhausted and divulged that David had philosophical questions about life and death. We expected that David would be depressed after this conversation, but to our surprise, it was the opposite—he appeared relieved, relaxed and was smiling.

Lesson Number 3

As previously mentioned, it wasn't until I met the nurse at the TCT that I realized that it wasn't a psychiatrist or a psychologist who could have "the conversation," but a highly skilled nurse. A nurse could have sat with David, listened and guided the conversation, and finally shared the information they had gathered with the healthcare team. That was when I seized the opportunity to make a difference. We had lived in London for seven years and I vowed I would plow through the obstacles entailed in making the appropriate changes back in the United States. I needed to develop a plan.

Lesson Number 4

On my return to the United States in 2007, I became involved with the School of Nursing at the University that I had graduated from. I was introduced to a nursing faculty member who was passionate about the needs of pediatric oncology patients and their families. She soon introduced me to the concept of palliative care—a team of professionals (doctors, advanced practice nurses, psychologists, social workers, and chaplains) all working together through the trajectory of a patient's life-threatening illness. Ideally, the concept would be introduced early in the process to help the patient with pain management, side effects of treatment, psycho-social support for the patient and their family, and holistic and spiritual care. They would prepare the patient

and their family as to what to expect throughout treatment as well as afterward. Fear of the unknown creates additional stress and emotional pain—the palliative care team would address those issues as they arose. If and when the life-threatening illness progressed, the patient and their family would be informed of their choices in care and decipher what priorities would be important to them. In addition, as the patient's health status improved or declined, the team would be there for them with guidance, providing continuous, transitional, and consistent care in the hospital and being a resource when they were discharged home or back into the hospital system. Support and continuity of care are the core goals of palliative care.

Lesson Number 5

I soon reestablished connections with the facility in which David was cared for in the last six months of his life. I realized that I wanted to fill the void that was so lacking in our son's care—psychological support for the patient and their family with a focus on advanced communication skills for healthcare providers. It just so happened that the medical institution had been offering formal advanced communication skill classes to their fellows, surgeons, and doctors. The cancer center was just entertaining the idea of extending the highly specialized training to advanced practice nurses in an adult care cancer setting. It dawned on me, why doesn't our family foundation provide funding for advanced practice nurses to learn this technique in the pediatric setting? The center was extremely receptive to the idea. Five years later, the program is flourishing with more than 70 nurse practitioners having received advanced communication skills through six specific learning modules. After didactic education, the nurse practitioners were provided an intense improvisational encounter with trained actors to replicate very sensitive and emotional circumstances (receiving bad news, preparation for death, questions on mortality, and wishes for end-of-life-care). The nurses, though initially quite unnerved by the improvisational simulation, realized they already had many of the skills necessary, but just needed additional education on how to navigate through the heart-wrenching scenarios. Several seasoned, experienced nurse practitioners broke down crying after the encounter with the actors portraying parents. The actors were incredibly convincing and my husband and I witnessed many of the various set-ups and were astounded at how real they were. A pre- and post-test evaluation was provided to judge how effective the program was, and all the nurses' feedback was extremely positive. Many requested follow-up practice sessions to continue improving their skills in advanced communication to their patients and families.

Lesson Number 6

Recently, my daughter Sarah earned her Master's Degree in Occupational Therapy and began work at a skilled nursing facility and outpatient rehabilitation center primarily dealing with geriatric patients. After several months of clinical experience, she mentioned to me how many patients would divulge, during their therapy sessions, their concerns about their mortality and fears of living in constant pain. She did not know how to handle her patients' concerns nor her role in this predicament. Initially, she told the nurse on duty and then her

supervisor but they too did not have the expertise to help the patient. It appeared to me that allied healthcare professionals would greatly benefit from basic training on how to respond if this encounter were to emerge. From my experience over the past 10 years of learning about palliative care and reading the literature on this emerging field, I realized there were several key knowledge points that are necessary for any healthcare professional who is not experienced in advanced end-of-life communication. I have shared these points with my daughter and she now regularly utilizes them, when necessary, in her own practice.

Palliative care is an emerging field in healthcare. In time, there will be more support for patients who will need to have “the conversation.” Palliative care will soon be integrated into all areas of healthcare, through the lifespan, especially in medical and nursing education. Through my daughter’s experience, as an allied healthcare provider, working in a skilled nursing facility and primarily dealing with an aging population, I believe that anyone caring for a patient with a life-threatening illness should learn the basics in advanced communication skills and how to handle “the conversation.” My son did not have this available to him due to the complexity of his medical care more than 16 years ago, but if other healthcare providers were able to handle the basics of supporting their patients, then they could have intervened and lessened the burden of the unknown for their patients. A patient’s sense of fear, uncertainty, alienation, and lack of communication with their healthcare team at this most critical time has to be identified by anyone who comes in contact with them. Knowledge of the basics of advanced communication skills has to be addressed in all areas of healthcare to provide full scope of care, medically, physically, emotion-

ally, and spiritually, to the patient and their families when they are the most vulnerable.

Lesson Number 7

As previously mentioned, it has been 16 years since David died. He would have been 32 years old in 2016. Over the past 10 years, I have seen a growing trend and interest. Several books on palliative and supportive care written by physicians have gained recognition and have been on bestselling book lists, including the *New York Times*. There is a growing momentum taking place in the field, and my husband and I finally decided that it was time to have our family foundation fund a center to educate nurses and other healthcare providers on the vital need to integrate palliative and supportive care into their practice. My hope is that nurses will take the lead in advancing this emerging field to the next level and will be at the forefront of research and state, national, and international initiatives. I know deep in my heart that David would be proud that his short life could contribute to the advancement of this movement.

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