

# “AM I GOING TO DIE, AUNT DEBORAH?”

BY DEBORAH S. RUSHING

**ABSTRACT:** *A nurse relays her experience with the death of her 10-year-old nephew, and offers resources for helping children and families facing death.*

**KEY WORDS:** *death and dying, end-of-life, palliative care nursing, pediatric cancer*

Death is not an easy subject. Death often feels like a “failure” for family and healthcare professionals, especially if a child is dying. We wonder what children think about death and if they’ve had enough life experiences to grasp the implications of death. And, we wrestle with why children must die.

Adults, especially parents, strive to protect children from dangers that lead to injury or death. However, we cannot protect them from all dangers, especially childhood cancers. According to the National Cancer Institute (NCI, 2010), the leading cause of death of children between infancy and the age of 15 is cancer. Cancer deaths have declined for adults but incidents of newly diagnosed childhood cancers have increased (NCI, 2010).

I enjoy the nursing profession. As a child I knew I wanted to be a nurse and a teacher. But at times I’ve found my nursing knowledge to be an emotional burden when diagnoses affect those I love. I identified my father’s oral cancer and later palpated a cancerous nodule in my mother-in-law’s breast. I have been with many family members and

patients for that final breath. It is never easy to watch someone die nor to see the grief their passing causes. With each death witnessed, I thought I had developed an understanding about death and dying. Over a span of 5 years, I participated in caring for my father, both grandmothers, and mother-in-law while they died from cancer. The major benefit I received from those experiences was a reaffirmation of my Christian faith. I learned



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to lean on God and trust him during times of trials. One of my life truisms became the Bible verse, “And the LORD, he it is that doth go before thee; he will be with thee, he will not fail thee, neither forsake thee; fear not, neither be dismayed” (Deuteronomy 31:8, KJV).

## NOT PREPARED

Despite this experience nothing prepared me for the illness and subsequent death of my nephew, Austin. He was diagnosed with Ewing’s Sarcoma at age 9. Unfortunately, at the time of diagnosis the cancer had already spread from his femur to spots on his lungs, hip bones, and other areas. I realized the enormity of his disease as I held his hand throughout diagnostic tests and exams. I used my nursing knowledge and experience explaining and clarifying tests and results to his mother, father, sister, and grandparents. I struggled with how much or little to discuss with them. During his illness, Austin participated in a research study on Ewing’s sarcoma, receiving chemotherapy, radiation, and various other painful treatments, but his prognosis remained dire. Austin’s paternal side of the family had experience with death, but his maternal side had limited familiarity with death or healthcare.

Austin and I had a unique relationship founded on trust and love. We had a mutual love of fishing, hunting, and the outdoors. Austin and I made a pact that we would always be honest with

each other. He was able to talk to me without worrying I would discuss our conversations with others in the family. Our relationship allowed me greater flexibility than other family members when assisting him during his illness and treatments, plus others were in various stages of grief. As noted by Kars et al. (2011) there are steps in the “letting go process” by the parents as they balance their grief with the child’s death versus continuing the struggle for life. I realized Austin and I had a relationship based on the “6 Es strategy” mentioned by Beale, Baile, and aron (2005): establishing a relationship, engaging the child in discussions at opportune times, exploring his or her feelings and concerns, explaining medical information, empathizing, and then encouraging the child through reassurance.

I was fortunate to spend a lot of time with Austin during his illness. I engaged him using open-ended questions in response to his concerns and questions. I supported him during painful tests and procedures and comforted him during long nights while other family members rested.

## AM I GOING TO DIE?

One night while holding him in his hospital bed, he asked me one of the hardest questions I’ve ever had to answer: “Am I going to die, Aunt Deborah?”

I could not deny the clinical presentation of his case and the seriousness of his prognosis. Many

years of nursing literature on death, dying, and children raced through my head. Parvin and Dickinson (2009) state children between ages 6 and 12 often view death as frightening and dangerous, as the Grim Reaper that comes in the night. Austin and I had previously discussed a primary fear—leaving behind his loved ones, especially his beloved sister, Morgan.

I wanted to hug Austin tightly and say he was going to be alright. However, the rules of our pact dictated I tell him the truth. Responding to his question, I said, “Yes.” I explained the treatments were not helping the cancer. He asked me to tell him about dying and what to expect. Austin always felt better knowing the details about what to expect or how something worked. Beale et al. (2005) discuss reasons to communicate truthfully with terminally ill children. As with adults, children experience fear of the unknown, which can increase anxiety and lead to disruptive behaviors. As I lay there, I asked God to grant me wisdom to answer Austin’s questions and help alleviate his concerns. Austin had attended church with my mother and my family and was familiar with Christian beliefs. I thought of Bible verses from which I found comfort and shared them with Austin such as, “And God shall wipe away all tears from their eyes; and there shall be no more death, neither sorrow, nor crying, neither shall there be any more pain...” (Revelation 21:4, KJV).

I whispered to Austin about God, Jesus, angels, and heaven based on my beliefs and interpretation of Scripture. I described heaven in terms I thought he could relate to as a 10-year old and as I picture it—a place with plenty of ponds, woods, and wildlife. It is a place where I will be with my Christian family, where cancer and other illnesses do not exist. I shared the verse, “The wolf also shall dwell with the lamb, and the leopard shall lie down with the kid; and the calf and the young lion and the fatling together; and a little child shall lead them” (Isaiah 11:6, KJV). It gave me comfort to think of Austin in a place where there is no suffering, where his leg would not hurt and he could run,



## Web Resources

- Children’s Cancer—  
<http://www.childrenscancer.org>
- Talking with Children about Death—  
<http://www.hospicenet.org/html/talking.html>
- Elisabeth Kubler-Ross Foundation—  
<http://www.ekrfoundation.org/pro-care>
- Improving Palliative/End-of-Life Care for Children—  
[http://www.nap.edu/catalog.php?record\\_id=10390](http://www.nap.edu/catalog.php?record_id=10390)
- Pediatric My Wishes—  
[http://www.agingwithdignity.org/catalog/product\\_info.php?products\\_id=85](http://www.agingwithdignity.org/catalog/product_info.php?products_id=85)



jump, and climb into tree houses without difficulty.

Austin commented, “But I don’t know anybody in heaven, Aunt Deborah!”

I asked him if he remembered his grandfather and great-grandmothers. I reminisced about them so he would feel like he could recognize them if it was possible to do so. He seemed comfortable with the notion of his grandpa being in heaven. Then Austin asked, “How will they come and get me when I die?”

Again, I prayed. I indicated I believed Jesus might send his grandpa and some other angels to meet him and take him to heaven. I told him he might be able to feel the angel’s wings stirring a breeze when they arrived. If my responses to his questions were too vague, he’d ask for clarification or my opinion. He wanted to know if he would have to “go right when they come for me?” I could see it distressed him because he did not really understand the concept of death and was unsure where his body and spirit would reside. I told him God’s angels would stay with him and not take him until it was the right time.

Austin wanted to know if he would be able to see his family from Heaven. I told him my belief he would see the rest of us on earth when he wanted to, but it would be different from how it was now. I told him the Bible teaches that as a Christian who has accepted Jesus as Savior I would be with him in heaven when I died. He seemed pleased to know more and I felt tension leaving his body as we cuddled in the hospital bed and his mother slept nearby on the couch. Eventually, we went to sleep and nothing more was said about dying.

Was I correct in my responses? I don’t know but what I said seemed right at the time. Was I truthful in this discussion of death and heaven? I am not sure as we don’t totally know what to expect after death. My responses were based on my thoughts, my love for Austin, my spiritual beliefs, and my nursing experience and education. After our conversation, I sensed a new level of contentment from Austin. I had told him the truth about his dying without hysterics or denial,

## I FELT CHILLS AS HE ASKED ME IF I COULD FEEL THE ANGEL WINGS MOVING THE AIR.




offering calm acceptance. Menten (1995) noted children often know when they are dying. After Austin gave permission, I told other family members parts of our conversation. Austin wanted me to tell the others he was ready to die. He felt he could not talk about his death with them as it made him feel as if he were “letting them down” or that they “might think I am being mean to want to leave them.”

Too soon, we went home with Hospice. It was hard to convince everyone to honor Austin’s request to go home; that if he died on the way home he’d be doing what he wanted. A few days later, Austin looked at me and said, “Aunt Deborah, they’re here!” I thought he was randomly talking as he’d been in and out of consciousness. I felt chills as he asked me if I could feel the angel wings moving the air. While pointing to where each of three angels were sitting he said he was not going with them “just yet.” He appeared more settled and restful. Too soon, he told us he was ready to go and he wanted us to come to heaven to see him soon. Shortly after that he died peacefully with loved ones at his bedside.

### REFLECTIONS

I pray I helped alleviate some of Austin’s fears and reassure him through presence, explanations, and empathy. Since Austin’s death I have searched the Bible for information on children’s dying, heaven, angels, and death (i.e., 2 Corinthians 5, Revelation 14). I’ve had discussions with religious leaders of different denominations about their perceptions related to heaven, angels, dying, and children. I have found comfort in Psalm 23:4, “Even though I walk through the valley of the

shadow of death, I will fear no evil, for you are with me; your rod and your staff, they comfort me” (KJV). I am not as worried about my own death, partly because of Austin but mostly because of my belief in Jesus and everlasting life. My experiences have deepened my faith and made me a more compassionate healthcare provider.

There are many issues to consider when caring for children who are dying. It is a complicated task, especially the emotional impact. Communication between healthcare providers, patient, and family members is key to providing optimal care. According to Hendrickson and McCorkle (2008), healthcare professionals must reflect on the child’s developmental age, the family dynamics, and past experiences with death. Consideration must be given to the patient and family members based on different theories, such as Kubler Ross’s stages of grief. As nurses, we need good information to provide the best care for patients and their family, to help pave the way for a “good death.” 

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