


Now and at the Hour of Death

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Abstract

With Alzheimer disease, the challenge of death can be unique to each who experience it: the caretaker, the family, the health-care professional, and the victim himself. Death of personality, of memory, and of physical skills wears away the fabric of relationships, leaving little hope of any return to normalcy. To some, this reflection exhibits how faith sustains hope and comforts those afflicted, despite the odds of inevitable loss. To others it reflects upon the poignant complexities associated with palliative care and the demand for individualized attention to the beliefs, norms, and values of each situation, no matter the culture, religion, age, or race. No two cases are ever the same in the face of death, yet for those who experience it, all must appreciate how difficult, unique, personal, and memorable such moments can be.

Keywords

empathy, end-of-life care, patient/relationship centered skills, patient engagement, patient perspectives/narratives, spiritual and integrative care, responsiveness, patient satisfaction

Momentarily we reconnected. Our eyes met for the first time in months as my father seemed to respond, “Yes. Let’s pray! We haven’t a moment to spare!” No, he was not dying right then and there; but his mind was. In that instance he traveled back to Algiers, 1942: “Pray for us who have recourse to thee,” he uttered, fearing the Germans would spot him working atop the telephone pole. For a fleeting moment, the Miraculous Medal, attached to the rosary in his hand, comforted him as it had once before. The present battle, however, could not be won. It was not with his fellow troops. It was his own battle and, in a way, a much more frightening one.

Only four days prior, Mom admitted Dad to the nursing home. At 84 years of age, his steadfast, sole provider was deteriorating more rapidly than he—both mentally and physically. The final realization came when Dad attempted to grab onto the television to hoist himself out of the couch. The entire TV set along with my father, tumbled to the floor, trapping him under its weight. Mom screamed for help, but no one was there. She had to let go—despite her feelings of inadequacy in fulfilling her promise to care for him at home to the end.

Mom was so thoroughly exhausted that she slept for two entire days after Dad was admitted to the nursing home. I thought it odd she did not choose to be at his side, but not even the doctor realized he would go so quickly. She chose instead to rest and contend with the ever-growing pile of soiled laundry, lost hope, and diminished dreams of a happy retirement. Mom never really cried. She kept on cleaning, preparing meals, changing soiled bedclothes, and counting

out pills. Yet, her deep sorrow grew as she knew in her heart her own strength could not withstand the challenges of this faceless disease. It was time to let go. She convinced herself he was in good hands, and she would now have more strength to enjoy his last days.

I too felt a sense of relief, as I worried about both parent’s strength. By day four of his stay, however, I returned to check on Dad before picking up my two children to attend a promised Broadway show. As I approached his room, I saw no sign of Dad and instantly panicked.

“Where is Stanley?” I asked the aide.

“Oh he is in the hall watching the nurses work,” she replied.

I rushed out of his room only to find an older gentleman dressed in my father’s blue sweat shirt and grey twill pants. His head drooped down to his chest, his gaping mouth oozed with drool, and his eyes stared aimlessly off into the distance. Who was this shell of a man trapped in such unfamiliar surroundings? He looked right through me.

“Dad! Dad!” I pleaded, “It’s your daughter!”

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“Oh, Stanley, is being a good boy!” answered the nurses for him. “He loves to sit here and watch us women work. Don’t you, Stanley? You love to keep us all in line out here!”

How could the nurses speak so patronizingly at my father as if he were a mere child? I was overcome with guilt, wishing I myself had cared for him instead of this institution and wanting not to leave—even briefly—to bring my children. I wanted myself they just might bring him back around.

Dad spent endless hours with his grandchildren—each in their own special way. Chloe entertained him on piano, while singing his favorites: “Moon River” and “Ave Maria.” He offered as much praise as he did supportive criticism. Chloe loved the attention. They bonded through music. As days passed and he grew distant, she continued to play, happy to witness the soft sway of his upper body and the twinkle in his eyes.

For Ian, it was basketball and football. Pap never missed a game if he could help it. Yet, as time went on, Pap was there less and less. Sadly, by age ten, Ian remembered him more for getting a bit lost driving home from the games than for his expert coaching advice.

“Did Pap really fight in the war, Mom?”

“Yes, Ian, he really did. He was a brave man, a good man, and a religious man, Ian. He always taught me if I were ever alone or afraid, all I had to do was say a ‘Hail Mary’ and everything would be okay.” Ian listened, but he was not so sure the man who told all those scary war stories was really the one lying in the bed before him.

That evening when we returned from the show, my father was worse than when I had left. We rushed into his room and saw him lying on a low bed, thrashing about, moaning, and carrying on in a way I had never seen. What had happened? Chloe turned her head away while Ian stared in disbelief. Perhaps, he was too young to understand. How I wished I had spared them from this unexpected sight!

Frightened by his anger and strength, my mind raced back in time to the very thing he always used to comfort me. “Dad! Dad! Do you want to pray? The Hail Mary? Remember how you always told me you would pray to Mary when you were in war, and it always helped? Remember?”

His thrashing stopped so abruptly it startled me. His eyes raced back and forth as if trying to remember; and then, all at once, they fixated deeply and intently upon my gaze.

Ever so slowly I said his beloved prayer. I watched his mouth whisper each word along with me. He had not spoken in days; and yet, miraculously, he prayed each word. We held the Blessed Mother in our midst, clinging together in hope.

I finished “Holy Mary, Mother of God, pray for us sinners, now and at the hour of our death. Amen.” Wanting the peace to continue, I hurriedly started again. “I’ll say the rosary all night long to keep him in this happy place,” I thought. No. That was not the case. As I uttered, “Amen,” his entire disposition changed. His loving eyes turned ice blue as if to say, “How dare you fool me! This is not *our* battle; it is *mine*!”

The thrashing resumed. The nurse hurried in to rush us out as if we were the cause of his rage. Reluctantly, I returned my children home and phoned the doctor who

recommended morphine. “It will minimize his agitation and facilitate breathing. We do this all the time when patients are in congestive heart failure,” the doctor insisted. In my heart I knew I said yes to the end.

The next day was his last. Mom visited early the next morning, witnessing him at rest. She was sure he mouthed a reassuring “I love you” as his final gift of thanks for her months of impeccable care.

Then, without warning the nurse broke the serenity of the moment announcing the morphine “high ball” in her hand. I resented her joke, yet smiled politely rather than upset Mom. I just wanted everyone to leave us alone.

Dad died peacefully. His right hand grew black, a cool breeze from the open window passed over us, and we watched my dear father take his last, long, shallow breath. The hour of death indeed came as peacefully as his final prayer.

Connecting with Alzheimer patients is difficult. No magic answer exists for how to reach them in their last days. Often the only thing that helps is to go back in time, to a safe time when things were happier and life, simpler. I am grateful for that moment I shared with my father and two youngest children. I am also grateful that Mom did not witness his terrifying agitation but instead held “I love you” forever in her heart. Dad fought his last battle with his family and beloved Holy Mary at his side, comforting him and giving him courage to face the inevitable. Perhaps the best gift we gave each other was the opportunity to share a special memory, a final connectivity with the past that would give his loved ones as much peace as it did him. We all remain witnesses to his battle, his courage, his life—as did all those who so nobly supported him in his last moments in the best ways they knew how.

Author’s Note

All characters in this article are authentic. This is my personal experience. Slight changes have been made to protect identity. Children noted are currently over eighteen and have given full written consent to share this story.

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