

# Between a Beginning and an End

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Desmond and I met between a beginning and an end.

For me, it was the beginning of my clinical years of medical school, the first day of my first placement. I was allocated to the respiratory medicine ward, tucked in the top corner of one of Australia's most large and well-respected teaching hospitals. I arrived with my notebook in hand and my stethoscope dangling conspicuously around my neck. I felt abuzz with nervous excitement and energy, carrying with me that powerful wide lens of attention that arises when you step into an unknown culture and environment for the first time.

For Desmond, it was an ending. He had presented late to the hospital with end stage metastatic lung cancer, and he was to spend his final days in a white hospital bed separated by thin grey hospital curtains from the three other male patients who shared his room. My career as a future doctor was beginning, but his life was ending. We met here for a moment in this sacred space of coming and going.

The first time I saw Desmond I was struck by how painfully thin he was. The bones of his wrists and hands protruded at sharp angles, his head was all skull and cheekbone. He had a shaved head with week old tufts of grey and white hair around the rim and a neatly trimmed beard holding to his angular face. I could see from his chart he was 68 years old, but he could have been 98 from the way his skin hung and his limbs surrendered meekly to gravity. As the registrar asked her daily questions Desmond responded with an exhausted indifference, and eventually he concluded our meeting by turning away from us to face the window. We continued the ward round and moved on to the next patient. Consumed by the rich newness of the hospital process and enamoured with the idea of myself as a future doctor, I did not think of him again.

The next day when we went to see Desmond we met a different man. He sat up in bed, his deep brown eyes enormous and shining with tears, he apologised again and again. He was not himself he told us, and he was sorry to be rude yesterday. He reached out his stick and knuckle fingers and held the hand of the registrar he had turned away from the day before. Caught off guard by his magnanimity, as his behaviour the day before had been more than understandable given his condition, I shifted internally and saw more clearly the whole person in front of me. Not 'the cancer patient in bed 9', but a complex and conflicted human being, struggling with the fast and unanticipated approach of his death.

A mentor of mine had told me in the months earlier that medical students are the "last bit of fat left in the system". The time of every other person in the hospital environment has been cut away to such a fine sliver in the pursuit of efficiency and

cost saving that spending extended time with patients is almost impossible. Sitting at a patient's bedside beyond the strictly limited time required to extract the information relevant to their medical treatment is not just an indulgence, it may be an act of negligence. There are other patients who desperately need your attention and medical expertise, so to spend the time required to know a person's story and see them as whole may deprive another person of essential medical care. This is not a lack of compassion on part of the doctors, it is the result of a health system straining under the realities of too many sick people and not enough healers and resources to help them.

But medical students are the exception. Medical students have all the access to patients and none of the direct responsibility for their care. It is a rare and astounding privilege to be medical student. So for the remaining weeks of his life I began to sit with Desmond every day. I felt powerless to help him in any tangible way so I did the one thing I felt I could do. I listened to him.

I sat at his bedside, lowered the bedrail, and listened. I had done some reading beforehand and, attempting to be a good medical student, I thought perhaps an academic approach would provide me some guidance to bridge across my chasm of experience. Perhaps I could support Desmond's journey through the five stages of grief of the Kübler-Ross model (1969)? Perhaps there would be some pamphlet on palliative care resources that I could provide at an appropriate moment? I felt an undercurrent of desperation in all of this, searching to try and find some way to help.

Desmond did not want to talk about his death. He did not want to recount his regrets, or to ask questions about his condition, or to talk about himself. He wanted to tell me about Genevieve.

Genevieve had been his love. Late in life, after an unhappy marriage and a hard and long career as a labourer, he had met a woman who he had deeply loved and who had loved him in return. He told me of her tenderness, of her joy and enthusiasm for life, and with a fresh and present grief he told me how she had died from brain cancer five years earlier. Genevieve was raised as an only child by two grocers from a small rural town, who had not wanted a child and made this known to her throughout her life. Desmond told me that she had felt unwanted and unloved, and even in her death her family had treated her with indifference. But as an adult she had met Desmond, and they had shared a heart of love for more than a decade before she died.

This is what Desmond wanted to tell me. Desmond asked me to hear and hold a story not of his life, but the story of his love. In South Africa there is a term, *ubuntu*, which describes the way in which we are all connected through our common humanity. Archbishop Desmond Tutu explains this to mean that "a person is a person through other persons" (Dalai Lama, Tutu, & Abrams, 2016, p. 60). Through Desmond telling me the story of Genevieve, his story began to make sense. He had known the symptoms of his cancer long before he arrived at hospital and yet he had seen no doctors. Why had he not sought out treatment when his cough started, when his back ached at night, when the blood appeared in his urine or his muscular body

rapidly shrunk away under him? Through listening I began to understand that when Genevieve had died, perhaps a part of Desmond had decided not to go on living.

When Desmond could no longer talk, I would return after the morning medical round and lower the bedrail, sometimes to hold his hand, sometimes just to sit with him in silence. I felt a sense of guilt about this, as though I was doing something wrong and unprofessional. Once as I sat silently with Desmond while he drifted in and out of consciousness a doctor from my team walked by and glanced at me quizzically through the curtains. I leapt up and pretended I was checking some medical detail in his chart before hurrying off to another bed, hiding my embarrassment behind a shield of busyness. I felt ashamed. I was afraid that this soft part of my character was a weakness and that it would stop me from being a good doctor.

And then one morning, his bed was empty.

Vainly hoping he had been moved to a nearby room I asked the team about him, and was told that Desmond had died overnight. I felt the full body whack of emotional overwhelm. The doctor must have sensed this as she looked up at me from her paperwork, and told me calmly that he had passed at 2am and as far as she knew he had not been in any pain. The conversation felt tight and was quickly concluded. I held my tears behind a mask of rigid professionalism. We moved onto the next task, and no more was said of Desmond.

This man passed through my life for only a few weeks, but the gift of the time he spent with me has stayed with me, and continues to inform my reflections on communication with patients. Deep listening is one of the most valuable things we can offer to another human being. In the hospital environment, it is almost an impossibility to approach every patient in this way because of the lack of time and resources. But we can set an intention to try. One moment at a time.

Deep and present listening can be as deeply nourishing for the listener as it is for the speaker. When our medical treatments do not work in the way we hoped they would, when our patients get sick despite our best and most diligent efforts, when we have completely exhausted our clinical knowledge of how to heal, we still have things to offer our patients. These gifts come not from our decades of medical training but from our own raw and present humanness. From the gift of being a whole person, witnessing another person's suffering, and deeply listening to their life. To accompany someone in this way is an act of being, rather than an act of doing.

I have wondered if the threads of Desmond's life and mine had not crossed at this early stage in my training, would I have seen this man and learned all that I did from our time together? In the famous Good Samaritan study (Darley & Batson, 1973) the predictor of whether a participant would stop and help a person in need on the street was not whether they had been recently reminded of the parable of the Good Samaritan, but how hurried they felt on the way to their next appointment. Despite our best intentions, hurrying prevents helping. The hospital culture of busyness may mean we are missing these rare and precious opportunities to connect, not only to

serve our patients better, but also to nourish and sustain ourselves as compassionate healers.

I would like to think that I would have taken the time and attention to be with Desmond as he died, but I fear that once I had seen and learned more about the hospital environment and how medical professionals are compelled to practice, I may have emulated this busyness as a path to professionalism and completely missed this precious opportunity to connect.

Desmond told me Genevieve's story, and through it he told me about his life, his love and what truly mattered to him. He taught me the importance of deep listening and how much we can do by bringing our humanness to the bedside along with our professional expertise. I understand now that the desire to connect and see people as whole is not a weakness. There is a power in listening and truly seeing people as whole that will not only serve our patients, but may also hold the key to maintaining our own wellbeing as healers in a hospital culture of disconnected busyness.

*Names and personal details have been changed to protect the privacy of the patient and their family.*

## **Bibliography**

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