

'End-of-life Care: the Spirituality of Living when Dying'

Melinda Ziemer



'Die before you die.' - Hadith

Before I trained in psychotherapy, I volunteered for two years on a hospice ward ¹. When people hear this, they often ask me how I managed to feel comfortable 'talking to dying strangers'. Their question suggests that we have forgotten Plato's injunction: 'True philosophers make dying their profession.' Those who know they can no longer elude death may, for the first time, undertake the lesson of the philosophers: how to die before their death. As a hospice volunteer, I learned this lesson with them. I felt privileged to have the 'strangers' I met at the hospice open their hearts to me before their earthly deaths. From these souls - both sorrowing and joyous - I learned much about how a few moments of attentiveness can open up a soulful space, potentially transforming 'end-of-life' care into new beginnings and living lessons, not only about how to die but also about how to live more fully, more aware of the soul's nature, needs and fulfilment.

Take Peter, a man I'd never met before, who took my hand in his and rubbed it between his own, saying 'your hand is so full of life. I've got to rub some into me.' The next week, he asked me to sit down and share a beer with him. I was running late for work and had only meant to stop in to say a quick hello. Not being much of a beer drinker, I couldn't manage to finish the entire glass. 'But you haven't finished yet!' Peter said, sounding disappointed, as I made ready to go. I thanked him for his company and said a hasty good-bye. The next week, when I stopped by to say hello and have a chat, he lay in a coma. I sat down silently by his bedside, and when he moaned, I placed my hand on his smooth forehead. His eyebrows moved slightly in response to my touch. His body still felt tense with life in spite of the morphine. I told him I was there and would keep him company longer this time. Later, I found out that he died alone during the early morning hours of that night. I told myself that the next time a person invited me to sit down and have a drink I'd finish the last drop.

Another day on the ward, I noticed one woman sitting up in bed holding her head in her hands, rocking back and forth. Strangely enough, she'd draped a knitted blanket over her head. Not sure how to approach her, I entered her room saying that I'd come to water the flowers. I thought if she felt like talking, she'd do so. And, in fact, she removed the blanket from her head and smiled at me with saucer eyes set above sharp cheekbones. She cheerfully explained that the light hurt her eyes. Then she asked me to take a seat in the oversized chair next to her bed. Given my own weariness, that chair felt like a blessing, but what came next was even more so.

¹ (Names and personal details have been changed to protect the anonymity of those in end-of-life care.)

Catherine started talking about the different lives she'd lived during her lifetime and about her work and her faith. Her eyes shone out from the dark circles around them. She took deep breaths between sentences and sometime between words, and I could tell that talking used up much of her energy. Still, every time I suggested I should let her rest, she insisted I stay and rest in the chair. It was as if she felt she had a job to do, as though she knitted a blanket of words from the many different strands in her life. In the end, I stayed with her for some time, inspired by the courage and strength she showed in her life and in sharing her story with me. She kept saying, 'That's my life' and laughing with childlike pleasure. Catherine returned home, where she died not long after our conversation.

Another time, I approached a man who lay motionless on his bed and asked him if he wouldn't like a tea. 'Why do you ask me that?' he whispered. I leaned down towards him and told him it was just a pretence so that I might sit down by his bedside and be with him. He replied, 'I'm dying, you don't need any pretences. Come and keep me company.' I did so and we sat in a comfortable silence for a while.

Not every encounter opened up so easily. I often think about one man who lay propped up in his bed watching television. His arms stretched out listlessly along his thin body, the palms of his hands turned up. He looked very near death. When I walked in the room and asked if I could get something for him, he slowly turned his gaze from the TV and stared unblinkingly at me, not making a movement. For a moment, I held his gaze, but then he turned away back to his television program without saying a word. I simply walked out of the room mumbling my apologies as though I had entered it by mistake. Perhaps he hadn't understood or heard me. Perhaps I looked confused by his silence. Whatever the case, as he turned away, I felt that I had missed something I ought to have understood and still regret that my own fears outweighed the momentary trust he had placed in me when he turned towards me.

I know from experience that if you're not afraid to look into the eyes of the dying, you'll often find that their eyes wordlessly reveal the secret beauty of the innermost self. For me, the dying gave a new meaning to the expression the 'eyes of the heart'. One desires to respond to that gaze with a look that says, 'I understand that all the fullness of your life is in this moment and that it is an honour to be able to look into your eyes. The approach of death doesn't frighten me. I want to be here with you. This moment is yours.' I remember Julia whose friends stood by her bedside telling her that she'd be up walking in no time. As they spoke, she turned away wearily and caught my eye as I stood at the end of her bed. The two of us didn't say a word. She just kept her eyes locked on mine, and we had a wordless conversation that felt timeless—she knew she would never walk again on this Earth, and she needed someone to know this with her. Julia smiled as she turned away again in response to a friend's touch. She died soon thereafter.

One morning on the ward, the nurses asked me to spend some time with an 'agitated' patient who didn't want to be alone. I was told he had a brain tumour and was confused. Steve seemed very happy to talk. I brought him a cup of tea, and he started to show me pictures of his children. He slipped in and out of coherence, repeated himself, and then would say, 'I've probably told you that many times.' Then he announced, 'I'm dying, you know. I know I'm dying. My family doesn't like me to say it, and it used to really make me sad, but now I think it's funny.' The doctor had given him pamphlets about dying. One had the title 'Death in Camden.' He thought it sounded like the name of a detective novel and laughed about it. Then he returned to the reality of his approaching death. 'Not everybody wants to hear about

it, my dying,' he said.' 'It's okay if you tell me,' I responded. He explained, 'I know that I'll die from this. That's the way it is when you have a brain tumour. They want to do some more procedures, but it's all over. My family doesn't like me to talk like this...' After that he wanted to describe how it was to have a brain tumour. 'Sometimes, the problem is I don't know my right from my left. It's like a game. Which direction should I go? And when I go there, I find out it was the wrong direction or I don't know why I went there.'

The next week when I went in to see Steve, he tossed back and forth in his bed shouting, 'I've got to get off, get off!' 'Get off what?' I asked. 'Off of this life,' he answered. Then he cried, 'I'm dying, I'm dying, but that's okay, isn't it?' 'Yes,' I said, 'that's okay.' He told me that trains kept going by and he couldn't get on. Knowing that the dying often dream of trains, I told him, 'Don't worry. You've got a ticket and when your train comes, you'll have no problem getting on.' He said, 'Yeah, yeah, I've got a ticket.' He seemed greatly relieved and fell asleep. He died a few days later surrounded by his family.

Though it seemed to me that most people spent time in the hospice alone, without friends or family to accompany them, sometimes I also met the family members of those I spoke with on the wards. I would end up bringing the family tea and talking with them in the lounge. I came to know one mother during the weeks her son, Paul, was at the hospice. He'd been there just under a month, and he and I had spent time talking together. One day, when I saw his mother in the lounge, she asked me to go sit with her son, so I went to see him again. When I came in, he said, 'Tell me something about where you're from.' I could only think of the California landscapes that meant so much to me, so I told him about the foothills, the coast, the deserts and the mountains. He didn't say much and went quiet. After some time, he said with a great effort, 'I want to talk but I can't.' He invited me to watch one of his favourite TV programmes with him and his mother.

At the end of the programme, I said my good-byes. He took hold of my hand and said, 'You don't have to go.' I told him I'd be thinking about him. I came in just three days later to see him again, but he had died that morning. His brother asked me to sit with their mother while he packed up Paul's things. She and I talked a good while. Early on, I said, 'Maybe you'd prefer to be alone.' 'No,' she said, 'Don't go, I'm glad you're here.' Her words reminded me of what Paul had said, and I could imagine him saying to me 'You see, you're spending time with me after all!'

Not everyone on the ward was close to dying. There are people who stay there for respite care to recover from their illnesses or surgeries. One such person, Michael, a short stocky man with a grizzled face and a broad chin, started talking with me in the lounge. When he realised I was a volunteer, he asked me, 'Do you believe there's an afterlife?' As soon as I answered, 'Yes,' he raised his fist in the air and asserted, 'Well, I tell you, I don't believe, I *know*. I had surgery for a brain tumour. I wanted to die. I had so much pain. And I did die on the operating table. I saw the other side, I did, and I'm not afraid at all now. I know there's something there. Saw my grandchild who'd died and my old friends. Some people here are afraid of death, but I tell them they don't have to be afraid. It's like going out to the pub to meet your friends. That's all it is.' He paused and asked if I believed him. I assured him I did. He explained, 'I don't talk about it with the folks back home. They'd think I'm touched.' I told him a dream I'd had about seeing my own mother on 'the other side.' 'That's it!' he exclaimed. 'It's all real!' His declaration of 'I don't believe, I

know' reminded me of the words of the psychologist Carl Jung who, when asked if he believed in God, had replied in the same vein same decades before.

Often on the wards, I would come upon someone taking a painstaking walk along the hallways. I can still see John who slowly made his way back to his room, one hand gripped the railing, the other his cane. I walked up to him and asked him if he would like some company on his walk. We chatted about his day and then he suddenly said, 'It's good you people come in to visit and all. You don't know how grateful....' At that he broke off and said, 'Look at me an old man getting all emotional.' I felt grateful for his words. The truth is, that day, I hadn't felt sure about going onto the ward and had even hesitated to enter.

I could tell that each word cost John a great deal. He talked about his pain and then made an immense effort to ask me about myself. His efforts touched me deeply. Over the following weeks, I met with him and listened to stories about his neighbours and children. He'd often say, 'Nice of you to listen to an old man go on about things,' and I'd assure him that I found his stories worth listening to, and that he was good company for me. So often people on the ward felt that I gave of my time: the truth is I felt they gave me generously of theirs. John recovered enough to return home. It was a special privilege to have been his private audience.

But nearly all those I came to know inevitably died during their time at the hospice. This seems the nature of life in a hospice and brings to mind one of life's great mysteries: that all of us will die, but few of us consider our deaths before we die. Those experiencing 'end-of-life' care approach this mystery, many for the first time, and most welcome some companionship, no matter how momentary, on the way. I think again on how complete 'strangers', near death, invited me into their lives and how they taught me to see and to hear everything twice - with both the mind and the heart - so that I might make living soulfully my profession.

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