

# ***Medical school: An introduction to death***

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A blessing and a curse of a medical career is being regularly confronted with your own mortality. Most people will go through non-medical careers and not give their mortality a second thought, only sporadically confronted with the introspection inherently present at funerals. As a 20-year-old starting medical school, I had never previously thought about my own death. I was young and energetic, my health was bountiful and the people who surrounded me were the same. At university, I learned about life-threatening and debilitating conditions and memorised their facts, then left my lectures and went home.

It was only when I started my first hospital placement that I learned of the feelings beyond the facts: the impact of illness on people's lives and, in turn, the impact on their deaths. At the hospital I was surrounded by people in many ways the opposite of my peer group – elderly and wise, their health failing and death approaching. I learned quickly that perhaps age is just a number, but health is not forever and eventually death greets us all. From those who were closer to death than I, I learned that some people were sorrowful and grieving while others were curiously ready, even asking, for death. That inevitably led to a certain curiosity about what my own death would look like. What would it mean to die? How would I meet my death? Would I have any choices?

So, along my medical student journey I decided to explore this idea of death. I wanted to know how people felt about their own deaths, and what gave them meaning in the process of dying. I wanted to know what a 'good death' looked like or, indeed, if there even was such a thing. And, if I found a good death, I wanted to know whether the healthcare system helped grant this to its patients.

My first experience talking to a terminally ill patient was with 54-year-old 'Mary'. Mary wore a headscarf and had a beautiful hand-knitted blanket overlying her white hospital bed sheets. She was a terminal head and neck cancer patient, in hospital for complications from her chemotherapy. After introducing myself and exchanging pleasantries, I asked Mary what she thought made a good doctor. I like asking patients this question. Who better to inform me of what it means to be a good doctor than patients themselves?

Mary turned to me and said, 'The best doctors really listen to their patients. It really makes a difference when you feel as though your doctor is listening to you.' She went on, 'For example, no one wants to listen to me when I say that I would like to go home.'

Mary had recently been told she had weeks to live, and her only chance to add a few extra weeks was to continue with chemotherapy. Much to her children's dismay, she had decided to refuse further treatment and had asked for palliative care. And much to her medical team's dismay, she had no interest in living any longer and wished to be discharged from

hospital. She was so young and yet regarded death so warmly that I was taken aback. So I asked her what she wanted to do with her remaining time instead.

'If I had the strength, I would march right out of this hospital', she smiled, 'I would buy a red convertible car, and drive up the coast blaring Billy Joel and Elton John'. I smiled back. Despite knowing Mary for only five minutes this dream seemed oddly in character.

'I would holiday with my family and when I felt ready, I would drive myself right off a cliff and end my life there and then.'

My 20-year-old self didn't know how to respond. I had never had someone express openly suicidal thoughts to me, and I was taken aback by her directness. And yet I felt I was being helpful in allowing Mary to play out this dream to someone willing to listen. I understood that, to her, this definition of a good death was a stark and beautiful alternative to her dying of her cancer in hospital. When we finished talking, I left the hospital feeling disturbed knowing it was unlikely Mary would be afforded her dream. It felt unjust to me that she was so desperate to die a 'good death' that she would be willing to die earlier, and yet she had neither the means nor strength to have that choice.

I will always remember this head-scarfed woman in G73 who taught me that living well can be more important than living long. Mary taught me that there was such a thing as a 'good death' and that affording choice allows dignity and respect in life and in death.

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My second lesson in death was my first introduction to palliative care.

Charlie was a 78-year-old man I met in the Coronary Care Unit who didn't realise how gravely ill he was'. He had been admitted for complications post-NSTEMI with a background of congestive cardiac failure. When I first met him, my impression was of a frail, round British man who was jovial and kind in the way he communicated. Every ward round he would ask the consultant what they thought of his condition, always making sure to address them as 'sir' or 'ma'am'.

'I'm grateful for your time, sir,' he would say to each doctor, 'I promise I'm doing my best'.

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In Coronary Care, the ward consultant rotated every week. One of ten cardiology consultants would appear on the ward each Monday morning, ready to apply their knowledge to the heart-troubled patient at hand. When Charlie met Consultant One, both were cautiously optimistic. Everyone was assured Charlie would make a slow but steady recovery from his NSTEMI. Consultant One deployed physiotherapy to encourage Charlie to move from his upright position in bed, and nurses were told to encourage him to be more independent.

The next Monday, Consultant Two arrived and met Charlie for the first time. Over the weekend, Charlie had been requiring increased oxygen and a bedpan, and was having difficulty sleeping due to agitation. On the ward round, Charlie was puffing by the bedside,

and appeared a shade paler than the week before. Charlie told Consultant Two, 'I don't feel myself getting better, sir' and Consultant Two replied, 'Don't worry, we have a few more options to explore yet.' Consultant Two tweaked the medical regimen, stepped up the oxygen to non-invasive ventilation and added IV antibiotics. Charlie also asked whether he could have something to help him sleep. He was struggling to fall asleep at night, stating he was feeling anxious. This concern was shared by the nurses. Consultant Two replied he would rather not provide medical sedatives at this time but advised Charlie to try to stop napping. Consultant Two reminded Charlie to accept help from physiotherapy because he was developing pressure sores. Charlie nodded forlornly but politely and used a handkerchief to wipe away his sweat. At the end of the week, Consultant Two reminded his registrars to have Charlie's Goals of Care form signed.

On Monday of week three, the RMO hurriedly ushered me into Charlie's room. 'Charlie needs an arterial line, and it is a good procedure for you to watch,' she said. In the crowded room, nurses were attaching ECG leads, a registrar was prodding Charlie for the line, and a Fellow was doing a bedside echocardiogram. Charlie had deteriorated acutely overnight and Consultant Three was dutifully investigating his deterioration. Charlie appeared to be only half present, groaning softly, and turning his face towards the fan whirring next to his bed. I moved outside the room, acutely aware I was in everyone's way and unable to provide any help. A nurse outside stood next to me, a frown on her face.

'It always happens like this', she said, unprompted. 'The consultants come in each week and think they can fix the complex patients from the week before, and by the time they realise they can't it is the weekend.'

By the end of week three, Charlie unequivocally told us, 'I don't want to keep doing this, I am dying'. Consultant Three informed us this indicated that the patient was 'losing the will'. He was refusing nursing care and food and asking for his family. Until this point, his family had been disallowed from visiting the hospital due to being unvaccinated. Charlie had spent three weeks, highly agitated, in the same hospital room and bed, wholly alone. Because of hospital policy, Charlie's unvaccinated family would only be allowed to visit if Charlie was transferred to palliative care.

The next week, I found Charlie fast asleep for the first time during my placement. His blinds were drawn closed, and his assemblage of beeping bedside monitors had disappeared. Charlie looked truly peaceful, and a part of me felt immediate relief. A purple file had replaced Charlie's usual files, and I asked my RMO what this meant.

'It means he's under the palliative care team now', she replied. 'We don't look after him any more.'

His medications were now given through a pump, regular observations had been ceased, and only minimal nursing care was required. Over the weekend, Charlie's family had been allowed to visit him. They had been distressed and shocked to hear their father was so severely unwell but had had time to say their goodbyes. Charlie passed away the following day.

Charlie's experience was my first exposure to the palliative care service and, to me, it seemed to represent a saving grace for him in his final week of medical care. Without realising it, I had been struggling with watching Charlie deteriorate in pain and had felt his comfort and wishes had not always been prioritised. He had been asking for assistance with sleep and family visits long before he received this care.

I later learned the limited palliative care treatment I had observed for Charlie was a poor example of what palliative care can do for patients. Charlie's care did not demonstrate the modern philosophy of palliative care as a holistic service employed early for improved patient outcomes. Instead, the service had been utilised as a last resort after disease control had been lost. My impression was that Charlie knew he was going to die, he had lost the will to go on, yet he only had the chance for expert palliative care intervention in his final three days. For three weeks I had seen him suffer with anxiety, insomnia, invasive medical intervention and lack of family visits, and he had appeared a broken and scared man.

Charlie's death was less expected than Mary's and the chance to ask him what constituted a good death for him was missed. In an alternative world, Charlie would have been recognised as a patient at risk of death during his hospital admission and referred early to palliative care. The need for frequent contact with his family would have been identified and offers would have been extended to implement advanced care planning services. Questions regarding Charlie's personal, emotional and social needs would have been asked, as well as how he would like his death to look. All this would have been done in the interest of affording Charlie the greatest dignity possible in death.

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Harry's death was my favourite. Harry had multiple system atrophy (MSA) and the disease had reached its terminal stage. Harry had an indwelling catheter and a wheelchair and was struggling to eat without medical intervention. Although he had a failing body, Harry was able to speak and was cognitively well. Having been informed of the likelihood of death from his disease, Harry and his wife decided that a death from MSA did not sound ideal. Determined to subvert death's cruel plan, Harry enlisted the services of the Voluntary Assisted Dying (VAD) team of his local hospital. The VAD team informed him that he was indeed eligible for the service, and that after the appropriate protocols, he would be able to pick up the medication to end his life at home. Harry and his wife told only family and a very few people that he would be undergoing VAD due to the practice being somewhat discordant to their own and their family's Christian faith.

Towards his later days, Harry was becoming easily tired and more strongly voicing his will to die. His wife, at a similar age of eighty years, was also increasingly unable to support him at home. They had lived for fifty years in a home they had built together and wished to finish life in the same place they had begun it; as such, Harry would have to die soon for their wish to be granted.

On Harry's final weekend, he and his wife told the family it was time to visit for their final goodbyes. Over the whole weekend, Harry received visits from far and wide and, by all accounts, showed enormous physical and psychological strength to allow everyone their

time to say goodbye. With family, he joked and recalled memories that others had previously forgotten. With his wife, he said thank you for the incredible love in sickness and in health. With nursing staff, he said how grateful he was to be pain free and have been afforded the choice to finish his life in his home and in peace.

The day he died, only the family who had been told surrounded him, and stayed by him as he drank his VAD medication. His last words were jokes to the effect of, 'Turns out I'm harder to kill than you'd think,' and, 'Go Tigers' and, lastly, 'God bless you all'. After his passing, and with appropriate time spent with Harry's body, his family carried him on a homemade stretcher to the edge of his property to the funeral staff. The hearse had been told to park at the end of the driveway, so that no one other than family would have to set foot on the property during Harry's final weekend. His death was entirely his own, absent from pain, conflict or distress.

Harry's death is my favourite because he was afforded his 'good death' through the VAD program. Whilst I respect the wishes of those who are unable to endorse the VAD program, I think its humanity and importance are difficult to disparage. In thinking of what would constitute my own 'good death' I would similarly wish to be granted such an experience as Harry's. His death was filled with such love and choice despite him suffering from a rare and incredibly cruel disease.

I will never forget Mary, Charlie and Harry, and their deaths will continue to inform how I care for dying patients from the start to the end of my medical career. I wish to contribute towards establishing a health service in Western Australia which is able to perform state-of-the-art palliative care for all patients and can afford people the choice of where and how they die to the best of its ability. In Western Australia, delays and ambulance ramping are impacting the ability of palliative patients to access care and there is a lack of infrastructure for hospice beds and Hospital in the Home services. I believe we can do better. I hope that as I embark on my medical career I am able to work towards 'better' and help more people achieve their 'good death'.

For my death, and for your death, I wish for a pain-free, peaceful and dignified passing, surrounded by friends and family. I wish for you to have opinions that are listened to, and for a healthcare service that is able to honour your choices. I wish for you to go as you came, loved and respected, earth to earth, ashes to ashes, dust to dust.