

One Person, Two Lives

Yoshua Selvadurai
University of New South Wales
Sydney

“Nice painting eh?” Ed said, pausing on the stairway and staring at a smudge of charcoal on an expanse of grey.

“Mmm yes,” I said doubtfully, hoping that we would not have to stop to admire any more works in *Storm Series II* on the way to the Chest Clinic. When guided to the lift, Ed had briskly veered away declaring “I always take the steps!” Now stalled in the hospital stairway, we were in danger of missing his 10.45am slot.

Sinewy and tanned, with soft brown eyes and shock of white hair, Ed looked strong and healthy to my inexperienced eyes. He wore polished black shoes, a brown belt with a bold buckle complemented by a perfectly ironed, shirt, adorned by a playful tie depicting the whimsical adventures of Snoopy. Ed informed me that he had driven six hours, without stopping once, from Canowindra to Sydney and planned to drive back tomorrow.

So when I returned the following week, I was surprised to see Ed lying in a hospital bed. As he saw me, an expression I did not recognise flickered across his face. Was it embarrassment? Anger? Maybe I had said something insensitive last week. And as our eyes met, he tugged at his hospital gown and called out for me to leave. Gently pulling me aside in the corridor, the Respiratory Fellow explained that Ed had been diagnosed with pulmonary fibrosis with twenty percent lung capacity and was refusing treatment, demanding to return to his work as a GP.

The Fellow explained that Ed did not have suitable support at home. His wife Jan was in a nursing home with early stage Alzheimer's disease. Dean, his only son, was a basketball coach in Pennsylvania. For the last few years, Ed had occasionally been a bit breathless when doing things like mowing the lawn or going up stairs, nothing he could not handle. He did not have time to waste in hospitals so he had been purchasing oxygen cylinders from BOC and treating himself. He had not told Jan about the oxygen. No room for both of them to be sick. Asked how much he took, Ed was vague. Some days when he was busy, he gave it a miss.

It horrified me to imagine Ed lying alone in a hospital bed. If nothing else, I could listen and provide him with company so that he would not feel lonely. However as Ed had strongly rejected me, I was uncertain as to the appropriate course of action to take. When I imagined that Ed was my grandfather and reflected on my expectations of how an honourable doctor should act, the decision was clear. I tentatively returned to Ed's room, explaining that he did not have to speak to me if he did not feel like it. Ed seemed to relax. Although guarded at first, he began to talk about his work as a GP. Pulling out his iPhone, he showed me an app for prescribing medications. As Ed explained the app, I realised that he had taken on the role of my teacher. He was not my patient, he was my mentor. Perceiving how Ed had always felt responsible for his patients and his small medical team, I realised how being helpless and vulnerable must be very new and unsettling experience for him.

Before I left for the day, I looked in again on Ed. Through the half opened door, I saw Ed sitting on the bed with his shoulders slumped, gazing out the narrow window. His eyes were not on the labyrinth of congested streets below but on the cloudless sky above. The iPhone had slipped off his bed and was lying unnoticed on the floor. The cruel irony of someone who had spent their life serving others, now debilitated by a disease which he had no doubt seen countless times, frustrated me and compelled me to conduct research on how I could better support Ed.

The next day I returned, equipped with palliative care pamphlets and communication techniques. This time Ed greeted me warmly, apologising for his outburst yesterday and extending a reconciliatory hand. I paused as I noticed his translucent skin and protruding cephalic vein, before gently accepting his hand, not wanting to hurt him. But Ed did not want to talk about his diagnosis or his treatment or any regrets. Ed wanted to talk about cars. Somewhat dismayed that my hours of research and practising communicating would not be needed, I hid the pamphlets, continuing to smile and nod. Ed said he had loved Formula One racing as a boy but had lost touch with it over recent years. With great passion he recounted the heroics of Michael Schumacher. Due to his fibrosis he found it a bit difficult to talk but I felt that he appreciated my respectful attention.

Over the ensuing weeks, I looked forward to our time together, especially the languid unregulated times on weekends and before and after timetabled classes. When I was not in the hospital, I would find myself thinking about Ed, imagining him laboring to breathe and feeling almost guilty to be respiring with ease. I hoped Ed was finding ways to distract and amuse himself.

In subsequent meetings, he showed me models of his favourite cars on his iPhone, including a 1962 Triumph Spitfire that he had hoped to buy one day. Seeing his eyes sparkle at the tomato red Spitfire lifted my spirit. I listened with interest as he recounted his childhood, of racing dodgy home-made billy carts on the flat, dusty plains of Canowindra and buying his first Holden HD. Yet, as Ed's condition deteriorated, his speech became significantly impaired. This made communication even more challenging but he would point at pictures and beam at my approving smile. I realised that somehow, in a strange way, pulmonary fibrosis had liberated Ed. He was no longer responsible for others and was now able to dwell on his own desires, experiences and memories. In these moments of aspiration and imagination we both sensed that his dignity had been partially restored. Optimistically and perhaps, naively, I perceived age not as a time of degeneration but as a time when childhood whimsy could be revived.

One day when I arrived with a copy of *Classic Cars* as a gift for Ed, I was confronted by an empty bed.

They say you die twice. "One time when you stop breathing and a second time, when somebody says your name for the last time." Alongside profound sorrow and emptiness upon Ed's passing, I never expected to later feel such incredible gratitude for having had our paths cross. Through reflecting on our interactions, Ed endures to shape me and hence perhaps our relationship continues to evolve.

As an inexperienced medical student faced with a seemingly difficult patient suffering from an imminently terminal illness, my initial reaction had been to let the Fellow take care of Ed. However, I decided to take responsibility and I am extremely glad I embraced this opportunity.

Medical students have little experience in pathology and pharmacology but we do have time and this was what I sought to provide. I am extremely fortunate to have the opportunity to acquire medical knowledge and skills to care for people. My interaction with Ed foregrounded that such care also includes empathetic emotional support. Perhaps I am naïve, just embarking on my career, but I truly believe that we can effectively shift from a purely clinical perspective to a compassion propelled health care system. Having experienced my mother suffer from breast cancer, I know how much a compassionate and committed medical practitioner can help a patient and their family in their time of greatest need. I do not remember exactly the names of my mother's doctors (and hopefully I will never see them again) but I cannot think of a better way to thank them than by extending the same generous care to the patients I meet. And for me, this journey of empathetic care started with Ed.

Ensuring that a patient feels as if they are the only person in the world has become a driving motivation for me. Appreciating that a patient is more than a collection of symptoms and understanding how their values and hopes have shaped them as an individual and providing complete care has become imperative. Surprisingly, I have found that adopting such an approach to clinical work makes it much more enjoyable. Instead of detachedly viewing the hospital as a conveyor belt of diseases but rather discovering every person's unique story and hidden needs is extremely edifying. I now understand that a patient-centred approach to doctor-patient interactions can enhance both patient well-being and doctor fulfilment. Seeing Ed beam during our interactions, really internalised for me the value of such a holistic approach and the importance of connecting with patients, beyond science, on a shared sense of humanity.

Unexpectedly, Ed also taught that peace can be instilled in the direst of situations. Sometimes I feel like we focus on what doctors and patients cannot do. Whether it be debilitating symptoms, limits to a patient's lifestyle or failed treatments, they can engender a pervading sense of anxiety. Watching Ed discard his confident blustery persona and reveal his inner self was extremely touching. Instead of mourning inadequate treatments, or the injustice of the disease, Ed returned to childhood endeavours. Whilst not discussing pulmonary fibrosis but rather exploring cars and recounting childhood incidents, Ed was able to cathartically purge his emotions (at times I wondered if anyone, apart from Michael Schumacher's mother, really could be so annoyed about a mistimed turn) and accept his mortality. By celebrating what Ed could do, think, smile, laugh, we were able to maintain a positive vibe that hopefully allowed Ed to enjoy, as much as he could, his remaining time.

Finally, Ed compelled me to totally reassess my assumptions as to non-compliant patients. I had tended to conflate non-compliance with images of obstinate individuals who refuse to enter hospitals or pay for medication because they would rather spend money on cigarettes. I felt a profound compassion for Ed and could not accommodate him within these narrow-minded stereotypes. My conversations with Ed's revealed how taking medication can be

viewed by a patient as an admission of defeat. Accepting medical care can form an admission that you are not as strong or as capable or as worthy of respect as you once were. And when you are sick, you desperately want to believe that the sickness has not changed who you are. And sometimes, holding onto being the person you were when you were successful is more important than life itself.

Ed continues to teach me lessons, and in this way, he still lives for me. I have learnt to accept that the diseases experienced by some patients mean that they cannot be saved on the basis of present day medicine. But in all instances we can expend our time and effort to nurture, support and engender peace within our patients. Ed taught me to embrace vulnerability by accepting what cannot be changed and celebrating what we can do. In this way, paradoxically, the effect of his life on me has been shaped by his death.

Yoshua Selvadurai, May 2019