

Sharing the Little Lights

Simon Chadwick
Sydney Medical School
Sydney

Names have been changed to protect confidentiality.

When I first met Alex, I was two weeks into my third year of medical school. Alex had brought his father Richard to the ED after 3 months of deteriorating health. Richard, an 85-year-old with no significant prior medical history, had become fatigued and dyspnoeic, and his loss of appetite had caused him to lose enough weight to concern his son. Richard's CT revealed a mass in his left lung, and several small lesions in his liver - he had metastatic lung cancer. From a medical perspective, the decision was simple - Richard required palliation.

I don't remember many of the details of that first meeting with Richard and Alex and the medical team. In classic medical student fashion, I was so busy trying not to miss anything that the important lesson of how to tell someone they're dying flew right past me. But I do remember the ease with which they both seemed to accept the path of least resistance. I remember Richard seemed like a kind man, and Alex smiled with the nervousness of someone who was standing tall because he had no other choice.

I also remember needing to leave the room. The image of Alex standing by his father reminded me too much of me standing with my mother, who had died of lung cancer four years earlier. I calmed down without too much trouble - a walk down the hall was all I needed. I returned to the room with the conversation about Richard's care ongoing - we would manage his pain, make him comfortable, and transfer him to a palliative care centre when a bed was available.

As his consultation finished, I asked Richard if I could return to take a more complete history; I sensed he'd be open to it, and I needed to do patient presentations for my assessments. However, the greatest motivator was a personal challenge - I refused to let the echo of my mother's illness stop me from speaking with a patient. So later that day I returned to his room.

In the hour I spent with Richard I got the impression of a strong and stubborn man. At no point did I sense he feared death. On the contrary, he accepted it with a fierceness both strange and admirable because he knew the fight was over before it had begun. Here lay a man who saw the unconquerable cancerous beast snarling at him, and he snarled right back.

But all of this is in hindsight. At the time I was more focussed on myself. The small victory was getting the history, the greater victory was sitting with a patient who had lung cancer and talking, laughing, showing no fear. But I feel ashamed to admit, that despite facing that fear, I felt tremendous relief in being able to separate myself from the familiar snarling beast lurking in that room.

Alex returned to see his father as I stood outside at the nurse's station, gathering my notes and my thoughts. We shook hands and he nervously wiped his palms on the back of his shorts. "How's he doing?" he asked.

"I think he's doing as well as can be expected," I said, mustering all the dispassionate diplomacy I could while trying to explain the obvious and inevitable in the vague yet compassionate way I believed to be expected of me. "His pain seems much better than it was this morning, so hopefully he's more comfortable".

Alex nervously shifted his weight from one foot to the other and his head turned from me to the door of his dying father's room. When he looked back to me, he spoke in hushed and urgent tones. "Do you think we're doing the right thing?"

Of course, I knew the answer was yes. This was an 85-year-old with metastatic disease – the curative treatment would be cruelly invasive and would ultimately fail. There was no cure here. But being new to the hospital setting had made me paranoid about making mistakes. I was training to be a doctor, a very important job that required my comments to be measured and tactful and reserved. Being reserved is the right thing to do. And that was what I had firmly in my mind as I uttered my next sentence.

"Well, I'm just a medical student, but..."

Alex cut me off. "I know, but I want to know what you think."

When I look back at how I responded to this statement I can confidently say that, at best, my response was accurate. I told him his father's disease was advanced. The team's plan was the best course of action. We would do whatever we could to make Richard comfortable. When a bed at a palliative care centre was available he could move there to be supervised by experts.

Everything I said was true. Alex even seemed somewhat satisfied. He nodded, we shook hands, he went to sit with his father. I went to present Richard's case to my registrar, got my form ticked off, went home, and felt very disconcerted by the way I'd handled myself. What's worse is that I had no idea why. I knew that if given another chance, I would do things differently, but I didn't know how.

I didn't see Richard for another week, but when his medical team and I returned, the man I'd met was gone. In place of the defiant Richard I had briefly known there was a quiet shell sunken in his chair. When asked if he was in pain, he groaned. He groaned again when his abdomen was pressed. A quick look at his bedside chart revealed Richard hadn't emptied his bowels in five days, and the team decided that he had opioid-induced constipation.

As part of Richard's assessment, the consultant asked me to perform a digital rectal exam. I got Richard's consent, and as a nurse helped me lay him on his side, Alex arrived. I explained to him what we were doing, and without hesitation he knelt beside his father and held his hand. As I performed this most intimate and personal of examinations, Alex stroked his father's white hair and smiled through sadness and concern and whispered that everything would be OK.

A few days later I ran into Alex at the hospital cafeteria. As we waited for coffee, we talked about the sweltering heat, about what I was doing in medical school, and about whether his sister would be able to make it to Sydney to see their father.

Then he said, "I just hope we're doing the right thing by him."

And this time I said, "I think you are". I told him about my mum, and how the decision to place her in palliative care was gut wrenching but nevertheless the right thing to do, and how it profoundly sucks to feel like you're giving up on someone. I told him that, as much as we like to pretend we're in control, sometimes that inevitable decision to let someone die is made for us by nothing more than a cruel mistake of biology, that what we could do instead was make sure that what happened was made more bearable, that any pain Richard felt was quelled until we didn't need to quell it anymore.

Something shifted in Alex. I could call it acceptance, or maybe understanding, but all I could see was that he wasn't shifting his weight as much, he was blinking less, and when his coffee came he smiled with his eyes. He thanked me and left, and we would never speak about his father's care again. But in that moment I felt like I'd connected with someone who was confused by the paradox of doing the right thing and still feeling guilty for it. I felt that instead of acting the politician and toeing the party line, I'd been human. I'd shared my meagre insight with someone who desperately needed to know whether the choice he'd made for his father was not only right, but kind.

To me, this is the crux of my doubt. I have insight into an experience of death that fortunately few people in my position have. I cared for a dying parent as a sole carer and watched her die before her time. I have grieved, and I still grieve. But instead of using my experience to sooth Alex's turmoil over choosing his father's death, I simply repeated a treatment protocol like a computer spewing forth an algorithm. My words were accurate but devoid of humanity. With my opportunity to try again, I allowed myself to share with Alex the frustration in our powerlessness to keep people like his father and my mother alive, that our hand had been forced by powers greater than any we could muster. I had related to him, fragile human to fragile human, and by sharing that fragility I had invited an opportunity to connect that hopefully made us both stronger.

Medical school has taught me tomes about how the body works. I've attempted to learn with intricate detail the muscles and nerves and cells and molecules that make up a human, and how we can cut up and drug up and take out what's needless or put back what's lacking. But what's missing from this are the common human experiences that a doctor needs to know about for the people under his or her care. Undoubtedly, one of these experiences is death.

The way medical school has taught me about death has been through talk of terminal illness, and a less-than-handful of philosophical lectures set between the volumes on which we'd be assessed. I learned more about death in the two weeks I spent with my mother in the palliative care setting, meeting the doctors and nurses and patients and their families and agreeing to a DNR and organising a funeral and sitting in the aftermath wondering, "What the hell just happened?"

The best suggestion I can make for how medical education could better prepare us for these conversations is by seeing them happen, by witnessing death. And the best place for this to

happen is within palliative care centres, where we can see that thing which terrifies us most, where we can sit with it as the sacred and inevitable phenomenon that it is. But the lesson for me is that instead of hiding from the beast, I can use my story to help people find their way. As mum was dying I felt lost, and when she died I was lost again. Somehow, through all that mess, I found a path, and the little lights that guided me might be shared with those who find themselves where I once stumbled.

I only saw Alex once more after that. I bumped into him at the hospital and he asked for directions to the transit lounge where his father waited to be transported to the palliative care centre; the place where he would die. Alex was with his partner, pregnant with a child who would never meet his fierce and defiant grandfather. I knew there was a good chance that for Alex, the process of grieving his father had just begun. I knew there would be moments in the coming months and years where he would try to call his father and the realisation that no one would pick up would dawn with bewildering obviousness. Maybe he would read something and excitedly think about how his dad absolutely had to see it but the thought would be interrupted by the reality that there was nothing he could share with his father ever again.

These were not conversations I could have with Alex. When I pointed him down the hall my role in his life had ended. But I hope that by sharing some of myself with him, he would sit with his father and there would be no regret or fear about his decision to let his father die.