



Into the darkness: medical student essays on first experiences of the dying patient

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As doctors, we often remember our first patient death; that particular moment when we realised that patients under our care can die. Those painful formative interactions with a dying patient are often etched in our memories.

While I knew cognitively that people didn't live forever, their deaths felt at odds with my prior expectations of being an effective healer. My first experience involved a male patient who presented with haemoptosis. When I clerked him into the ward, I discovered he had aortic incompetence. Although I had documented this as a still-unquantified anaesthetic risk, he was transferred to theatre for a bronchoscopy. I was standing at the patient's side during the procedure and found myself taking his pulse, intuitively worried something terrible was about to happen. He then arrested on the table and had major cerebral damage from which he never woke up. It took me years to understand just what had happened or why I was so upset about his death. (HW)

This issue of the Journal will publish two essays by Auckland University medical students, Rebecca Gandhi and Thomas Swinburn, about their first experiences of dying patients. These essays were submitted to the biannual writing competition of the Balint Society of Australia and New Zealand (BSANZ).¹ In 2021, there were 45 entries by students from a wide range of medical schools.

After initial sorting, the better essays were assessed in depth by a panel of international reviewers. Remarkably this year, 8 of the top 10 essays were about students' initial experiences and observations of patients who were dying. Many reviewers commented on this predominance. Student narratives

about the dying patient have already been described as 'painful and raw'² but what set these essays apart from other entries, and why had they engaged the reviewers so acutely?

There is now considerable research on the reactions and responses of medical students to the dying patient. Briefly, many students start their training with somewhat naïve expectations about the efficacy of medicine, beliefs that may be reinforced by cure-orientated pre-clinical curricula³ and if there is insufficient emphasis on or training in palliative care.⁴ Initially, students identify more with patients than with practicing doctors, and when they first enter the clinical phase of training, it can be profoundly shocking to get to know a patient who then dies.⁵

Just as illness can 'wreck' one's life story,⁶ such deeply disturbing experiences have been described as 'narrative wreckage' of a student's presupposed journey in training.² Scholars of narrative suggest that telling stories can help repair such damage^{7,8} through group discussion or reflective writing. As Shapiro suggests:

*'Storytelling serves as a method for healing students' initial sense of dislocation and purposelessness... through their stories, students begin the long process of reconciling their disillusionment with hope in and renewal of their vision of themselves as physicians.'*⁹

Medical training largely focuses on helping students develop their professional identities as 'technically skillful' and 'medically knowledgeable' practitioners. There is less pedagogical space devoted to helping them become 'caring and compassionate'.¹⁰ So unless there are superb role models who can

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demonstrate how to engage with a dying person,¹¹ it is challenging for students to learn how 'to be in the room' and to interact with those patients, especially if they or others around them have some degree of death anxiety.^{12,13}

The essays that follow are evidence of the initial apprehension and ambivalence of two medical students as they attempt to engage their own humanity in service of their patient.¹⁴ If attending doctors are perceived to be distant or uncaring,¹⁵ students can also experience 'moral distress'; their observations of clinical practice feel at odds with their own moral sense of what is right or what should be done.¹⁶

As we read these essays then, perhaps we are reminded of our own dissonance and discomfort when we first struggled with the contradictory tensions of clinical objectivity versus deeper engagement in relation to people who were suffering. Exposure to many thousands of patients over the years may fine-tune those tensions but arguably modern medical education also has a responsibility to nurture more deliberately the capacity of young doctors for empathy and compassion.¹⁷

Reflective practice in all its varied forms – discussion groups, audio-diaries, parallel charts, Balint groups, reflective writing¹⁸ – can contribute to self-awareness and emotional intelligence, as they focus on the interactions between student and doctor. These activities also focus less on medical details or content than on the process of clinical practice; how events unfolded and how the institutional context influences the outcomes.

Narrative reflective practice helps students to review and use their learning experiences thoughtfully,¹⁹ especially with respect to their own ideas about becoming a doctor. Reflecting on end-of-life care is particularly relevant, as those experiences can remind students of their own mortality and what sort of doctor they want to be. In New Zealand, medical students are encouraged to understand their patients' wellbeing through a *tea o Māori* lens that includes *Te Whare Tapa Wha* (physical, social, mental and spiritual domains).²⁰

As organisers and the reviewers of the essay competition, we noticed that the better essays had some

common features. All these students engaged well with a particular patient, often when others around them did not seem to have the courage to do so. Each student had made a real connection with their patient (*whakawhanaungatanga*), and in their writing, they wrote openly about their anxiety, self-doubt and *pōuri* or sadness about what was happening. This emotional openness may reflect a loss of personal boundaries in the dying patient, whose anxiety and suffering may then be received and experienced by the student.²¹

Interestingly, many students described how they used their own initiative and personal agency in service of the patient; spending extra time, listening and attending without a medical agenda, making space to hear the patients' *kōrero* or stories. All these actions contrasted with their usual feeling of being superfluous in ward settings. From those interactions, they made some useful insights about the nature of training, including significant shifts in their emerging perspectives about what it will be like to be a doctor. Lastly, we as readers were immediately engaged with each of these narratives.

So perhaps then, our resonance with these stories has something to do with recognising the student in all their courage and bravery. We resonate with the enormity of their struggle to engage and connect compassionately with the dying patient within a culture of medicine that defaults to clinical detachment and sees death as failure.²²

No wonder then, that the top 10 essays were largely about end of life care, which acutely exposes some of the major conflicts for students in their learning to become a doctor. Many students also commented on the personal benefits of writing their essays. Perhaps through crafting their stories, they gained some understanding of just what happened between them and their patient, and how they were currently negotiating their personal and professional identities.

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Homecoming

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‘You’re not going to get much out of her’, I was advised by a nurse as I went to admit our new patient. A quick end-of-the-bed examination: a Māori woman exactly my age, eyelids closed tight in a grimace, head shaved, skin yellow and mottled. Winona. She had been admitted to the hospice for end-of-life care, with an unrelenting melanoma that had metastasised to her liver and bones. She had had enough. She was angry and tired.

Winona was accompanied by her partner, a young Māori man, Jason. ‘Winona, I know it’s the last thing you want to do right now, but I need to ask you a few questions to see how we can help you’. This was received by several expletives and intermittent reference to the immense pain she was in. Quiet for a few moments, then, ‘Sorry, miss. I’m not usually like this. I’m just so sore.’ More quiet. The familiar anxiety that accompanies a distressing clinical situation settled in. More quiet. More expletives. More apologies from both Winona and myself. A little bit of help from Jason. Maybe the nursing staff were right. But, despite not getting a lot from her in the initial interaction, it was clear to me and everyone in the room that Winona was dying. What was not so clear was how much time she had left.

I sat quietly with her over the next couple of days. I was never able to push through her pained exterior and, although it was frustrating to not be able to connect in the way that I wanted to, I had an overwhelming amount of empathy for her suffering. Those carefully drawn lines demarcating the boundaries of the doctor-patient relationship seemed to disintegrate as I began to see her as a sister, a daughter, a partner, a friend. I respected her as a young woman who was fighting to maintain autonomy over the body that remained. Who was I to interject? I simply let her be, let her express her frustration, swear in pain, sat beside her and listened. We tried to manage her symptoms as best as possible with massive doses of opiate analgesia,

anxiolytics and antiemetics. Her grimace never disappeared.

A few days into her admission, the hospice clinical director consulted with Winona. He spent a lot less time trying to obtain a clinical history than I did. He focused on Winona’s story. We learned that she had been with Jason for eleven years. They met in school. She was from a small town at least five hours away, and many of her whānau still lived there. In sharing this story, the grimace eased a little, though it did not fade completely. The energy in the room changed. Instead of noticing the sadness, I noticed the love in Jason’s eyes. I noticed the unwavering support he had offered throughout her illness. The eleven years they had spent together was an old map, sprawled in front of me in the dimly lit hospice room. Then the clinical director asked, ‘Where do you want to be right now?’

‘Home.’

Up until that point, my time at the hospice had felt like wading through honey: slow, deliberate, often lingering. With one look at her condition, and a single request, things sped up 10-fold. We were going to get her home. All our options were weighed up – even a ten-thousand dollar helicopter transfer (that was quickly excluded). After hours of conversation with a domestic airline, a transfer via airplane was arranged for the following morning, accompanied by a hospice nurse. We were on track.

I arrived at work the next day and there were at least fifteen people outside Winona’s room. The air was solemn.

Winona had died at 4:50am – two hours and ten minutes before leaving for her whenua.

I accompanied my supervisor in certifying her death. Today, for the first time, there was no grimace. I couldn’t help but note that she finally

looked at peace. Before we left the room, I whispered, 'Rest easy, sister.' She was uplifted later that day to be buried at her urupā.

I think about Winona, months later. I see her in every dying patient I have encountered since. I see her in every unwell young patient, every unwell Māori patient, and in every unwell patient who does not consider this city their home. The first thing I was told about her, 'You won't get much out of her' was completely untrue. I haven't stopped learning from her.

She prompted me to think deeply about the connections our patients have outside of what we see. The Western model of healthcare places strong emphasis on bettering physical health. Even the palliative care model may not always account for the wider beliefs and core values of some communities. I reflected on the heartbreak that I felt when I learned we were not able to get Winona home and realised that this deep connection to the land is not solely experienced by Māori, but by my own culture too. Perhaps this was why it was so difficult for me to process. It led me to delve into the definition of home. Is home where one lives? Where they were born? Where their family is? Or is it something far deeper, more spiritual, is it the concept that all that we are, will return to the land that birthed us?

The answer lies in the very nature of being human – it's different every time. This is particularly evident in our diverse communities. So, the only way to know is to ask. Alongside effective medical management, health professionals need to start opening up conversations in parallel about what the patient hopes to happen after medical care, so that planning can begin appropriately. I cannot help but think that, if we had asked Winona what she wanted on the first day she was admitted, she would have died on her land. However, this doesn't just apply to end-of-life care, but to routine discharge planning on all hospital wards. Since this interaction, I have made a note to ask my patients where they are from and where they call home. In doing this, I have learned far more about my patients and have developed stronger connections that have allowed me to positively contribute to my team's decisions about treatment. I hope that bit by bit, this active work in understanding serves to improve faith in the

healthcare system, particularly from marginalised communities. There is always room for this kind of humanistic approach to medicine. It does not hinder the traditional method, only enhances it while running in parallel. As the world diversifies, so do we. We grow and we adapt with our patients. We learn about tradition and core beliefs from cultures that are not our own. This is how we continue to show compassion in life and in death.

Compassion may hinder judgement at times. In the initial interaction, I was able to see and acknowledge Winona's suffering, but I was not able to see beyond it. Because of our closeness in age, those doctor-patient boundaries had been blurred and I felt myself suffering alongside her. This prevented me from seeing anything outside of managing her symptoms. Ironically, it was a more distant approach from a fresh pair of eyes that was able to address her needs better, to allow her to tell her story on her own terms. In the interaction just before her death, the beautiful moment of storytelling I experienced with Winona, Jason and our clinical director encouraged me to see them as storytellers. These days, I take time with my patients. I let them weave their stories before I ask them what I need to know. As a medical student in my final few months, I know that time is a luxury that will dwindle on the other side of graduation. I want to utilise this luxury to the fullest extent, for both myself and for my patients. It is one of the most valuable things we can offer.

This piece on culture would be incomplete without highlighting the importance of returning to the land in the context of COVID-19. An article published recently on death and dying in New Zealand in the COVID era states:

*'This thing, tangihanga, it's ours. It is for the living. No one can negotiate with Hinenuitepō, but we can weep together at her feet. We can laugh. We can remember. We can and we must. It's how we begin healing, and as much as possible, that process must not be delayed. But a virus has interfered with the flow of this ancient river, so that now, a mother cannot leave quarantine to dress her son, to hold his hand, to make sure he is set for his journey.'*¹

Dying in isolation is a new threat to the cultural practices that have been kept alive for centuries.

As clinicians in this new age, we will need to develop strategies to keep tradition alive, respect the wishes of the dying, while protecting the wider public. This sphere warrants further research combining the approach of cultural liaison with appropriate public health and microbiological understanding.

When a patient dies in hospice care, a butterfly sticker is placed at their door. I never asked why. In a later attempt to make a profound reference, I researched butterfly migration patterns. My intended metaphor kind of fell flat because as it turns out, butterflies in New Zealand don't tend to migrate. But, at the end of the day of Winona's death, I went to the gardens nearby. I sat with the marigolds and cried. As the tears fell, a small white butterfly accompanied me in my thoughts, and I was filled with her energy. I knew she would be on her whenua by now, surrounded by all her whānau, soon to return to papatūānuku.

In my own culture, white is worn at funerals. I thought the butterfly may have been her, but as I am writing this, I realise it was probably a part of me.

A messenger, adorned in my white sari, set to migrate a few hours south. Just this once. To say thank you. And goodbye.

Names and specific details have been changed to protect the identity of people and whānau involved.

Māori translations (maoridictionary.co.nz)

whānau: extended family, family group

whenua: land

urupā: burial ground, cemetery, graveyard

tangihanga: funeral, rites for the dead

Hinenuitepō: spirit, receives the souls of the dead

Papatūānuku: Earth, Earth mother and wife of

Rangi-nui

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An unexpected journey

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At the orientation session on the very first day of our very first clinical year, the Head of School, whom I would later discover is also an oncologist, asked at the very end, 'Right, now who's Thomas Swinburn?'. Having been one of the last to arrive, I found myself in the front row and slowly raised my hand, bemused and sheepish in equal parts. On that day, in front of the whole cohort, I found out that I would begin my clinical placements with oncology. Little did I know then that this unexpected allocation would expose me to patients who would fundamentally challenge my perception of clinical medicine in this formative stage of my journey towards becoming a doctor. In this essay, I will share the story of my relationship with one of these patients, a Māori man named Ereuti*.

I first met Ereuti on consultant ward round as I was coming to the end of my first whirlwind week. Up until then, I had been largely preoccupied with trying to be helpful to the team, and simply keeping up without getting in the way. The medical team bowled into 14B*, I probably closed the curtain, and it was in that whitewashed room with sunlight streaming in that I first met Ereuti. He was a gaunt, pale man with sunken eyes in a hospital gown sitting silently in a chair, sprouting various lines leading to various whirring devices. Listening to Ereuti that day, I wondered whether he just wanted to feel a bit of normalcy; he asked us whether the nasogastric tube and catheters could be removed so that he could go home, and what would happen if he did. The consultant oncologist was sympathetic but didn't mince his words: Ereuti could go home, but without the constant infusion of intravenous nutrition, he would be making the choice to go home to die. Ereuti looked into his hands and said nothing.

As we continued the ward round, I found myself in a state of despondence and contemplation as I tried to

make sense of the enormity of the decision that our team had just laid before him. Later that day, my registrar suggested that I take a history from Ereuti. It feels uncomfortable to admit that my initial, visceral reaction was one of apprehension, for earlier in the week I had taken a history from a similar patient, and I had not managed to establish the connection I had hoped for, making for an uneasy if otherwise polite interaction. Memories of this past experience surfaced at my registrar's mere suggestion. As I walked towards Ereuti's room, I could feel myself carrying my biases down the corridor, and I found myself conjuring up worst case scenarios. I wasn't sure how to manage these thoughts and emotions, so I simply allowed myself to name them as being on my conscience. As I sat down with Ereuti and we began to connect, it quickly became apparent that our interaction would unfold neither how it had with the other patient earlier in the week nor how I had imagined it this time round. I felt caught between relief and a sense of guilt that I felt relief. These fleeting seconds served a powerful reminder that as doctors, despite what we and perhaps society might imagine and even expect of ourselves, we are not immune to the intrinsic human condition. Assumptions and stereotypes shape our interactions and relationships before we have even set eyes on the patient. The totality of our previous experiences, the way we innately identify self from other, and even more simply our basic human needs like hunger and sleep, can subconsciously interfere with our commitments to professional ideals. I believe we cannot transcend our human nature as subjective beings and clinicians, but a good starting point may be the ability to be honest with ourselves by recognising our real emotional reactions.

As our conversation took shape, alongside all the usual questions I decided to try something a bit different. In medical school, we're taught to ask

*Name and details changed to maintain anonymity.

patients about ideas, concerns, and expectations, and in the past I had seen these as nice, token questions needed to obtain distinction in end-of-year clinical exams. However, an intuition spurred me to ask Ereuti what mattered most to him now. After just a few seconds to catch his breath he replied, 'Regaining health and being able to live naturally once again. Being able to eat without this tube in my throat and to pass bowel motions naturally. Relationships. Not superficial relationships but deep relationships. Relationships where I can be myself. Money and career don't matter now.'

In the past, actors with whom we had practiced might have responded to such a question with something like 'getting rid of this knee pain' or 'returning to work as soon as possible', and reassurance with neat, prepared formulas was easily rendered. But here, sitting one-on-one with Ereuti, I wasn't prepared for an answer that felt as though it drilled down to the very essence of what it means to be human, even as I feared that some of Ereuti's wishes might not be able to be fulfilled. Here, I didn't have any charismatic stock phrases up my sleeve. Here, I couldn't tide the silence with a polite, empathetic smile before signposting into the past medical history. Instead, I remember being both mesmerised and somehow uplifted by his answer. I was struck by his clear sense of priorities, his yearning for dignity, and the resoluteness and certainty I detected in his voice. I sensed that he had had time to meditate deeply on the answer. It almost felt as though he had been waiting to have the opportunity to express his heart's deepest desires.

Over the next few days, I found that I couldn't help but ask myself the very question I had asked my patient. While I tried to reason that his perspective on the most important things to him had undoubtedly been influenced by his terminal diagnosis, it was both confronting and refreshing to undertake my own introspection. While Ereuti wished simply for a healthy body and meaningful relationships, my valorisation of academic and career pursuits, often at the expense of spending time with family and friends, seemed shallow and short-sighted in comparison. We've all heard the age-old adage that one learns from one's patients. I didn't just learn clinical medicine from Ereuti.

Instead, I couldn't help but be challenged to stop and evaluate my values, the journey I was choosing to steer, and what matters most to me, both now and when the time comes to look back on a life lived. As doctors we have a significant potential to serve, and we have an even greater privilege to be privy to the innermost lives of our patients. The doctor-patient relationship is one of reciprocity as is the student-patient relationship: while we give what we can, the insight and wisdom we take, perhaps often for granted, is humbling.

Over the next few weeks, I came to enjoy popping in to see Ereuti, sometimes for no other reason than to say hello. I felt the warmth of his smile as he recognised my increasingly familiar face, and I hope he felt mine. I made a conscious effort to spend just a little bit longer with Ereuti than I might with other patients, whether that be sharing some medical knowledge, attending to his comfort, or talking about our shared aspirations: for the bowl of grapefruit sitting on the windowsill to ripen, for Ereuti to return to his *tūrangawaewae* (place of belonging), for health equity in Aotearoa New Zealand. At times, I did harbour doubts about whether I was acting appropriately; while I felt our interactions were always professional, I worried that perhaps my allocation of time with Ereuti compared with other patients might be 'unjust'. If as a doctor I continued this practice of spending more time with some patients than others, would this equate to inequitable practice? I was able to reconcile this uneasiness when a mentor shared with me that inequity of input is required to achieve equity of outcomes. Looking back, I recognise that sometimes levelling will feel like privileging. In other words, the feeling that one's actions are privileging a particular patient might actually be the feeling of achieving an equitable outcome for that patient, or at least taking a step in the right direction. It is clear to me that equitable practice equates to professional practice.

Ereuti continued to receive inpatient treatment when my placement in oncology had ended. You can imagine my surprise when a few weeks later, I pulled back the curtain after talking to another patient on another ward, only to find Ereuti in the neighbouring bed, sitting up dressed in his own clothes with a big smile on his face, waiting to be

discharged. He was reintroducing soft foods into his diet and his bowels were moving once again. As we parted for what I thought would be the last time, he joked that I could find him catching 'kingi' off the wharf in Kawhia. As the months passed, I would find myself smiling, perhaps naïvely, at the possibility that he was still alive and fulfilling those wishes he had shared with me.

That was until I passed the palliative care doctor in the corridor. 'Ereuti's back. You might want to visit him, because this will probably be his last time in hospital.' I realise now that the significance of those words hadn't quite sunk in as I made for Ereuti's room, a spring in my step as if I were going to meet an old friend. As I reached his room and pulled open not a curtain but a door this time, I was taken aback to see that the gaunt man with sunken eyes had returned. 'It's good to see you again. I'm at peace with dying... It's good to see you again,' Ereuti managed between laboured breaths. While a part of me was ready to hear any final existential musings the 'master' might have for his 'apprentice', the space we once knew and shared had changed. I sensed that he just wanted some time alone. Ereuti had embarked on another chapter of his unexpected

journey. I said goodbye and we exchanged warm smiles for the final time.

As I reflect on my relationship with Ereuti over these months, I feel privileged to have learnt so early in my career that the practice of medicine lies as much in sharing our common humanity as it does in prescribing and intervening. Sitting alongside penicillin and morphine, listening and talking are tools we all possess in our medicine cabinets, to name just a few. Sometimes, a simple smile is top-shelf medicine. While I have no doubt that the plethora of lines and devices contributed to Ereuti being able to walk out of hospital, at least for a time, so too did the kindness of the medical, nursing, and support staff and their simple gestures, one human to another. When I set out on the very first day of our very first clinical year, I thought medicine was about diagnosing and treating disease. Through walking alongside Ereuti on his journey, however fleetingly, I am privileged to know now that it is about much more. As I embark on my own unexpected journey, while there are many technical skills to learn, Ereuti showed me that sometimes it is the human qualities we all possess that are the most powerful medicine.