Death: A reflection

Clare Ward

Correspondence to: clarity1@xtra.co.nz

My roots are Tauiwi. My ancestors arrived from England and Ireland by ship around the year of the signing of the Treaty of Waitangi. My father's family went farming and settled in Marlborough. I studied zoology first and then medicine and for the last 18 years have worked in Hokianga both as a general practitioner and also helping to run our small hospital. I really enjoy my work both because of its scope which takes in both beginning of life care (antenatal and intrapartum) as well as end of life care, and also because of the fact that the community I live in is a bicultural one. It has been a huge privilege to be able to be a part of two different worlds and world views.

'Let us begin at the ending, the ending of us all: begin with Hinenuitepo, the Great Lady of the Night, Mother Death. She is a fearsome lady, her private parts bladed with flakes of obsidian, her eyes of dark green jade, her hair the long black tendrils of kelp. And her skin – clear, red, glowing palely!'[1]

In Maori legend, Maui who was the trickster hero, half man, half god, set out to conquer death. He attempted to murder the sleeping Hinenuitepo by entering her vagina to make his way to her heart to stop it. Piwakawaka, the fantail, could not stop himself from laughing and his laughter awoke the goddess, who brought her thighs together and crushed Maui. If Maui had been successful human beings would not die, but instead *'He ai atu ta te tangata, he huna mai ta Hine-nui-te-Po'* (*'Man begets; Hine-nui-te-Po destroys'*).[2]

We talk of good births. We mean that our child will come into the world in a mindful way. We mean that it will come in the fullness of time, that it will come on the crest of a wave that has gathered to deliver the new life into arms that will protect and hold it against unseasonable danger. We mean that there will be a first breath, a first cry and a first seeing of light, eyes, breast.

We talk of good deaths. We mean that we will leave the world in a mindful way. We mean that in the fullness of time and after a satisfactory journey we will engage with our deaths, make peace with the past, complete whatever is left to be done in the present and die in a dignified and companiable way.

'A man dreams about himself.
He dreams he died.
He keeps feeling he's reached home.'[3]

We do not mean that our children will die in terrible ways before us. We do not mean that we will become tired and irritable and not know what the matter is. We do not mean that we will shake with fear and waken out of nightmares or that we will make bargains or plea with Whoever is out there to take someone else, not us.

We do not mean that we will beg for a final large dose of morphia or that we will sweat and complain or that our worlds will shrink into a mess of symptoms. We do not mean that our children, our sisters, our brothers, our friends will find excuses to leave us to it. The hard truth is that our entries and our exits are, in the end, out of our control. The tide comes in, it goes out. It brings life, it brings death. It leaves behind fish bones, shells, froth and it takes away traces of where we walked, where we stood and of the people we talked with.

Death calls us by name. Death does not call us by name.

Death alerts me the physician that it lurks in the room. Death fails to alert me the physician that it is anywhere about.

I feel complete in my art. I feel unworthy of it.

I am a good companion for the last journey.

I am flawed and I betray my patient's trust.

I am the keeper of comforts and dignities.

Box 1

The owl cries out to me,
The hawk cries out to me
As death approaches.
The killdeer, the mountain bird,
Cry out to me
As death approaches.
The black rattler, the red rattlr,
Cry out to me
As death approaches.
The red racer, the garter snake,
Cry out to me
As death approaches.
A large frog, a little frog,
Cry out to me
As death approaches.
An eagle, a condor,
Cry out to me
As death approaches.

Adapted from:
Helen Roberts. *Women's Dance Song.*[3]

I am swallowed up by things I do not understand and cannot control.

I know that my gift is valued and that I am welcome.

I am rejected because I have failed or because I have only bad words to tell or because I have nothing to offer.

This discussion is about failures rather than successes. It is about times in our lives when we are unshielded, when we are vulnerable, when we do not sleep because we cannot put to rest things we have done and things we have failed to do. Grief for a loved patient at the end of a shared road, when each of us understood the other and understood the struggles of the other, is easy grief. The tears or reflections or thoughts that come with it are comfortable ones. We know that we did all we could and that we gave whatever was in our power to give.

It is the other times when there was no success that is difficult.

Maybe someone came into hospital. They had a temperature, they had a cough. We diagnosed pneumonia. We prescribed oral antibiotics or maybe we gave them intravenous third generation Cephalosomething. That night they collapsed, their blood pressure was unrecordable, their oxygen saturations were in the low 80s and before we could even think the word, septicaemia, they had died. Maybe they were 62 or 63. Maybe they had children and grandchildren who had gone home, secure in the knowledge that their relation was being treated well. Maybe we had to ring them up and tell them the bad news. Later that night maybe we lay awake thinking about what we had missed or failed to take account of.

Maybe someone came into hospital another night. They had been involved in a car accident. They were wearing a seat belt but had hit their head. It was not a high speed accident and there was no loss of consciousness. They complained of a headache but not much else. They went home two days later. They still had a headache but not much else. A week later they collapsed at a party and they died. The post mortem found a subarachnoid haemorrhage. Maybe you read everything there was on the subject of post traumatic subarachnoid haemorrhages and discovered they are a rare but known phenomenon. Maybe you should have fought for a head scan. Maybe all of your patients get head scans these days.

Maybe you had a patient with lung cancer. She was scared of dying. She did not mind the idea of death but she did not want to suffer. She did not want to lose control. She did not want to frighten her children. She did not want to feel pain. You told her not to worry, that you had morphine, you could relieve anxiety and panic, you could give oxygen. You told her that her family would not have to feel the terror of those maternal arms clutching and groping and begging them to let her go. Maybe you should have acknowledged that sometimes those things happen anyway. Maybe you should have warned them about the death rattles. Maybe you would not have had to endure their anger and their recriminations. Maybe you could see them now and that raw passing would not cast its shadow between you.

Maybe you have another patient. He has motor neurone disease. He is unhappy. His partner is unhappy. Whatever you do is not the right thing. You spend hours with him. You listen as hard as you can and it is never enough. You cannot give him what he wants and he wants you to know that. You know it and you dread the visits but you go anyway. One part of being a doctor is putting the personal to one side. One part of being a doctor is knowing that you are a symbol for something else. In this case you are a symbol for failure. You know this, but somewhere inside you it eats away at you too. The motor neurone disease incapacitates the two of you.

Maybe our patient has hung himself. He has been sick for a long time. Maybe he had been agitated the day before but it wasn't the first time and all the other times he had shaken himself out of it. Maybe we had heard him a dozen times before and we were unable to tell that this time he was more desperate and was begging to be taken seriously.

Some of the failures we carry are personal and some belong to our profession. Sometimes it is because we overlooked a result or failed to interpret a symptom or because we did not listen to our patient carefully enough. Sometimes we wonder whether that patient would be alive now if only we were more vigilant, less judgmental, thoughtful instead of preoccupied with more pressing but less important things.

Sometimes we have to watch the return of a cancer after the chemotherapy is finished, the radiotherapy has been done, the offending bits cut out. Maybe it is five years later and there is a sore back or a bellyache or a falling off in appetite. Maybe our eyes betray us when the patient complains and it is our lack of faith that is the problem. We remember that bit in the Bible where Jesus re-

Box 2

They were calling out to us
They were looking at us
They were preparing the
Underground house of death
For us.
They found us,
Curlews, killdeer, and owls crying
Hoo hoo hoo hoo oo
Turn back, Everybody turn back
West, down to the ocean,
Your spirits, your hearts
Everybody turn back west
Toward the ocean,
Cottonwood, kelp,
Turn back, go back
Down, the place of
Your spirits, your hearts.

Adapted from:
Helen Roberts. *Pimukval Song of Temecula*.[3]

minds us that if we have as much faith as there is in a grain of mustard seed then all things are possible. We have to argue with ourselves about what belongs to the realm of faith and what belongs to the realm of medicine. There is that grey area we all know about. The patient gets better because we believe she is going to. What does it mean when that does not happen?

There might be a young man who used to play representative rugby. No one can say why his heart has suddenly stretched to four times its usual volume and why he cannot even walk a hundred yards now. Nobody can save him from dying even though on television miracles happen every week.

Maybe we did do our job well. We did organise tests and procedures and specialist visits. Maybe those things failed too or we were reassured when nothing was found and we assumed too, that nothing was there. Again maybe we should have been reassured less and trusted more. Maybe his wife has died now, of lung cancer. *'She had those symptoms for a long time,'* he says. *'Perhaps if they'd found the cancer earlier...'* He is not angry and not really asking us for an explanation. What is there to explain? She felt something in the back of her throat for a year. She had her barium swallow and her endoscopy. She had her chest x-ray. She was not the type you would usually describe as hysterical but there she was, labelled with the globus syndrome, or *globus hystericus* as it was once called.

There is a story from an old book about a youth and Godfather Death. It involves a contract between the two of them. Godfather Death will make the young man a famous physician if he will obey certain rules. Only the physician can see Godfather Death in the room with him. If he stands at the head of the bed then the patient will live. If Godfather Death stands at the foot of the bed that patient will die. The physician may not save a life that belongs to Death. In the story the physician becomes successful because he is able to say who he can heal and who he cannot. In the end he tries to trick Death by turning the bed around and in the end he is forfeit to Death.

Today our medicine seems unaware of the contract. Atorvastatin, aspirin, heart bypass surgery and stents return patients to safety. A cardiac death is our failure and not Death's lawful quarry.

We question ourselves as though we were the arbiters, as though the power to redeem belonged to us.

Our patient has unstable angina. We send him off and he gets a stent. He is grateful and happy. About a month later he returns with the same symptoms. All of us are surprised but he goes away again, gets anti-coagulated, his stent gets freed up and he is grateful again but not quite as certain of things as he was.

He dies suddenly. We are not quite as certain of things as we were. We believe that we can save lives that would once have been lost and it is true that our 90-something-year-old patient who had his heart operation three years ago is still riding down the hill on the back of his boy's quad bike. It is also true that our 48-year-old patient, who came in only a week or two back complaining of a bit of chest tightness and who went down to Auckland for angiography looking terrified as she was wheeled into the back of an ambulance, came back in a hearse. She went through her bypass operation

Box 3

I feel like a vulnerable
Pa-site, sacked, by
An unforgiving enemy
Force & razed to a level
Unbecoming, to a warrior-force,
But – freed at last
To accept – with humility –
The earth-smelling pungency
Of that Grand Dame – mother
Of us all: Papa-tu-a-Nuku:
Our Earth-mum.

Hone Tu Whare[4]

Box 4

Come back
Before you get to the king-tree
Come back
Before you get to the peach tree
Come back
Before you get to the line of the fence
Come back
Before you get to the bushes
Come back
Before you get to the fork in the road
Come back
Before you get to the yard
Come back
Before you get to the door
Come back
Before you get to the fire
Come back
Before you get to the middle of the ladder
Come back

Adapted from:
Frances Densmore: *Song for the Dying.*[3]

and then her heart slowed down. The autopsy showed blood in the pericardial cavity. The autopsy said that this is one of the known possible consequences of surgery. We remember how pleased we felt that she was getting her chance and now there is a hollowness inside that has not filled itself up yet.

Sometimes our treatments actually cause death. Someone who was previously healthy reacts to something we prescribe and the outcome is not just a rash or aching muscles or nausea but is mortally and immediately life threatening.

A man comes in with gout. He has had it lots of times before so we decide to start him on Allopurinol. He has a fatal desquamation reaction – the first we have ever seen, the only one we have ever seen. If he had taken his Indocid instead maybe he would still be here. We continue to prescribe Allopurinol, we continue to prescribe Indocid. Some of our patients will die of renal failure and gout. Some will suffer because of the gout. Some will be jeopardised by the treatment.

In the end and to go back to the beginning, to Hinenui-te-Po, Goddess of the night, of the world of darkness, of the world of death, we go back and confront our own mortality. We confront our mortal inabilities and weaknesses as physicians and healers.

Our flaws contain our strengths. Our strengths contain our flaws. Our patients will continue to suffer in ways they wish they did not. Sometimes we will know we could have done it better. We will make new mistakes, discover new pitfalls, feel new disappointments, be afraid again. We will also go forward again and try again. We learn by our mistakes and it is our mistakes we remember – not our successes. Someone who died 20 years ago lives on in our practice today. It is often the failures and errors, the unexpected and unwanted outcomes that make us better doctors – better in our craft, better in our art and better in our communication.

Box 5

Light the first light of evening, as in a room
In which we rest and, for small reason, think
The world imagined is the ultimate good.
This is, therefore, the intensest rendezvous.
It is in that thought we collect ourselves,
Out of all the indifferences, into one thing:
Within a single thing, a single shawl
Wrapped tightly around us, since we are poor, a warmth,
A light, a power, the miraculous influence.
Here, now, we forget each other and ourselves.
We feel the obscurity of an order, a whole,
A knowledge, that which arranged the rendezvous,
Within its vital boundary, in the mind.
We say god and the imagination are one...
How high that highest candle lights the dark.
Out of this same light, out of the central mind,
We make a dwelling in the evening air,
In which being there together is enough.

Wallace Stevens. *Final Soliloquy of the Interior Paramour.*[3]

Competing interests

None declared.

COMMENTARY

Clare Ward's personal reflection on death, poetically situated in our country, demands not a well sourced peer-reviewed response, but rather like with like. One could comment that for each of her salient points there is a review article: on a 'good death'; 'cancer treatment'; 'medical mishap' etc. But in the end, Ward's reflection is more insightful than many of these articles – she captures experience – contextualized and profound, real and unforgiving.

Yet forgiveness and spirituality in its broadest sense are thoughtfully examined. Ward calls to mind the times when there is 'nothing to offer' or, worse, when a fatal mistake is made. She is mindful of these experiences and asks, not in any righteous or overt way, but rhetorically of 'Whoever is out there', what are we doing? Such awareness, even in the impersonal objectivity that modern medicine claims, suggests one's self, one's humanity, one's resonating spirit can still be present, and grow with and beyond such experience.

I have spent the last three years talking with and surveying people with terminal illness, their family members, staff who care for them and Maori 'experts'. One of my reflections is that after all the apparent failures – of the medical system and drugs, of one's body, of one's faith – death is not the failure, but our attitude towards death may be. Peace of mind is the need and often experience at life's end for many New Zealanders, despite our prevailing death-dying culture. The illusion of medicine's curing capacity incapacitates us all. As Cicely Saunder's reminded us, there is potential for growth and healing to the last breath (and, I'd add, this growth is not just for the patient, but for all of those connected to the death).

Richard Egan
Teaching Fellow, PhD student, studying spirituality and dying. Dunedin School of Medicine, University of Otago.