

Medico Legal Talk Observations on Death

Introduction

Thank you Ian Civil, for the invitation to speak and also to rejoin the Medico Legal Society that both Ema and I first belonged to for a brief period, many years ago. In those days I had a mop of dark curly hair and worked a house surgeon at Middlemore; Ema is just as glamorous now as she was then. In those days, she was working for Chris Field, out of an old villa, equidistant from the Otahuhu Court and Sam Woo's Vietnamese restaurant. Sam Woo regularly hosted lunchtime meetings of the "South Auckland" Medico Legal Society at which my colleagues, casually dressed junior doctors from Middlemore, would eye up those universally flash looking lawyers with suspicion, usually over piles of wontons and roast duck noodle soup.

My topic this evening is not Vietnamese cooking, it is a more serious and universal one, death.

To be specific "Observations on Death and Dying: an intensive care doctor's perspective."

Before I start, let me say that Howie advised me not to take it personally if a few of the lawyers dozed off after dinner and during my address. I won't. Once being purposefully provocative I caused my audience of surgeons to stand up, puff out their chests and walk out. My skin has been well thickened by past experience.

Given the nature of this audience let me begin with a disclaimer:

I am an ordinary bloke who so far has been lucky in life. I have had few personal experiences of losing loved ones. The one time that happened, the death of my father, 19 years ago at the age of 78, I responded in a very ordinary and mortal way. I was a confused wreck. I certainly am no more of an expert in personal loss than any of you, many of whom, I sadly suspect, will be more experienced than me in this regard. My talk this evening is based on my experiences from a different and particular place.

That is from the position of an intensive care specialist at Middlemore where I have worked for the past 18 years. Each year our staff directly manage the care of about 1000 patients. Roughly 12% or about 120 of those people die in our ICU. That job description bestows upon us the great privilege of meeting and getting very close to families who's loved ones have experienced illness, injury and tragedy, often unexpected and sudden.

What I intend doing this evening is to give you some context about intensive care practice, at Middlemore Hospital in particular, tell you three patient stories and conclude with some observations.

Most metropolitan ICUs in Australasia are closed units. This means that all decisions to admit and discharge patients, all charting of fluids medications and other treatments can only be done by Intensive care staff, not by the patients' original physician or surgeon. They hand over the care of their patients to us. In a well integrated and functional unit, the patients are managed with considerable input from the other specialties as needed, but no matter how well intensivists foster relationships with other staff, tribal differences arise and the ICU commonly gets accused of being a silo.

Our service at Middlemore, altho far from perfect, is a good one. This is how we work:

- We are a specialist led service where nothing happens to patients without us knowing
- We have 24/7 resident medical cover
- With 1:1 nursing care as part of a tight team
- Together with families we establish short, medium and longer term treatment goals
- We allow open access to families with whom we inevitably establish close relationships
- So when the need arises we can sit down together to have discussions about difficult and painful issues in an honest and open way
- As a result, each year, our ICU seldom receives a single complaint

For these critically ill and injured patients we are as much health care brokers as we are health care providers.

Intensivists are involved in the resuscitation, diagnosis and definitive treatment of the critically ill and injured. We also conduct an orchestra of surgeons, anaesthetists, and all manner of physicians to bring together their experience and skills to do what's best for our patients. Whilst all that goes on we provide them with organ support (ventilators, drugs, dialysis machines etc), to buy them time in the hope that they will have the strength to survive and make a decent recovery.

We actively manage our patients. Put simply, it's about BEING THERE, doing things, seeing the results of those interventions and adjusting what we do to move toward clearly understood and articulated goals...weaning patients from ventilators, improving their circulation by using volume resuscitation and cardiac drugs,

All this happens on the Intensive Care Unit.

As well as that, we spend an enormous amount of time seeing and assessing sick patients in the emergency department and on the wards;

It became apparent to me early on in my career, that the results of the interventions and things that we do to people are more related to who we do it to, than to the things that we specifically do.

The analogy with panel beating is a good one: think of a clapped out old car in the same crash as a new car. It is pretty obvious which one will do better. How robust and well we are before we get sick is significant in how well we will weather the storm of our illness or injury. That is largely the realm of public health: the stuff of education, socio economics, housing, labour and the like;

How well we do is also determined by how quickly and effectively we are treated..that is more in our immediate control, so too is whether or not we take a fall or a series of slips on the banana skin of our health services. I am talking medical error here....that too is in our control and in the realm of patient safety and quality.

When it comes to the treatment of an individual, this is where the art of medicine intersects with the science.

In places like this, Auckland NZ, in 2009, my impression (tell me if I am wrong) is that you, the public, expect your doctors to be up to date with the science: aware of the evidence base for what they do and have the relevant technological and scientific expertise that goes along with their qualifications; The art comes in applying that to the individual patient in front of them, to do the right thing for that person at that time, knowing too that the decisions they make for one has implications for others.

For patients and their families, an admission to intensive care is deeply stressful. Our job is to help them understand what has happened, what the treatment options are, and ultimately to lead them to a point where the right thing to do for the patient becomes apparent.

To do that we need to fulfill a number of roles.: to be the medical expert AND in a very short space of time to develop a relationship of trust with the wider family by making time to listen, to take an interest in the life of our patient, to get a feeling for their values and beliefs, to get to know them, to be honest, compassionate and understanding...in essence to be human.

Our job is to involve them in the decision making process but at the same time to unburden them of the responsibility for the clinical decisions that are made, especially if they involve a change of emphasis in care, to a move away from full on organ support to comfort care....the responsibility for making those decisions have to be ours. Now, there's a talking point!

These are intense and deeply moving times for families (as it is for us too). How successful we are in serving them well either as individuals clinicians or as a service, depends on the quality of the relationships we have built with them.

Success for us is complicated..spending time in Intensive Care is not the same as getting your car rebored...we do not always produce better cars....there are some things We Can Do, some things We Could Do But Shouldn't, and plenty of things We Simply Cannot Do. Communicating and resolving these heavily loaded choices with our colleagues and families is the real guts of Intensive Care practice. The way we manage that with individual families is to work towards a common understanding of what has happened to the patient, the seriousness of their current position and its likely consequences; once we get there, it is our role to present a plan to the family, one that they understand and can accept.

There can be no worse deceit to a patient or their family than pretending to be able to do what we cannot do; to pretend to be able to fix what we clearly cannot fix; to prolong someone's death under the false pretence of a resurrection we cannot deliver upon. In those circumstances and for those conversations, the quality of our relationships and how we project and connect as human beings, more than any other thing, determines what we might all recognize as success for us, our patients and their families.

No matter the outcome, and especially following a death in our ICU, this is what we want our families to remember about the way things came to pass:

We hope the family can walk away knowing that they have been dealt with honestly, openly and fairly; that their views were respected; that their loved one was given world class care; and that in the end, what happened, happened because it was the right result.

Three stories, seriously anonymised, might better illustrate some of these points and form the basis for some concluding observations:

1. The first story concerns the unexpected death of a previously healthy person.
2. A second, illustrates the added complexities of needing to make decisions within decisions..this story about potential organ donation in a patient who became Brain Dead.
3. The third, an increasingly common scenario: managing the expectations of families and patients in the setting of an acute deterioration in the health of a patient with significant co-morbid disease.

The first story:

One Xmas morning not so long ago I met Mr A. He was on a ventilator in our ICU in an induced coma. He was a 60 year old man from another country, a devout Muslim, still plying his trade as a farmer. A previously healthy man, he was here in NZ visiting his grown up children and seeing his grandchildren. He was not here to access health care, he was not here seeking asylum. He was like any one of us: visiting their family in London or any where else on the planet;he was an ordinary decent man who had a great life and a loving family.

The day before, xmas eve, at around midday he had complained of a headache. This got worse as the day wore on and eventually got so bad that at around 10pm, he pitched into our emergency department. A couple of hours after arriving, he quite suddenly became unresponsive, lost consciousness and stopped breathing. He was quickly resuscitated and ended up intubated on a ventilator. To the medical staff who were treating him, it appeared like he had suffered some kind of intracranial catastrophe, a bleed or a catastrophic stroke?

He underwent a series of tests to figure out what was wrong with him. These included blood tests for microbiological and biochemical analysis; a CT scan of his head and a lumbar puncture to sample the fluid from around his spine..all of these were normal.

By this time it was 3am and he was moved to the ICU.

He was the first patient I saw on the round that xmas morning. I stopped the propofol infusion, a short acting anaesthetic drug which was keeping him asleep in order to better examine him.

There are a limited number of causes of ongoing unconsciousness. This is not a neurology class so I won't go into them now but many of them had been already ruled out.

Whilst we waited for the medication to wear off, we organized for an MRI of his brain and brain stem to be done later that morning, then I examined him.

Good morning I said to him, introducing myself and telling him where he was. There was no response. Open your eyes I said to him. To my surprise, he did. It soon became plain that he could hear me perfectly well and could understand what I was saying but that he was profoundly paralysed able only to open and move his eyes. My clinical examination suggested that he had suffered a brain stem stroke and was locked in. Those of you who have read the Diving Bell and the Butterfly, will be familiar with this condition. Mr A was only able to communicate with movements of his eyes. We quickly established a means of communicating a simple yes or no, with him blinking twice for no and once for yes.

After a time I explained to him what I thought was wrong with him, confirmed with him what he clearly knew, that he couldn't move any of his muscles apart from those of his eyes and reassured him that his family were near. I explained that we needed to do further tests to determine exactly what the cause of this was and to help us guide any treatment that might help. I then asked him whether he would prefer to be asleep or awake whilst we went about this. He clearly indicated his desire to be kept asleep.

This was a terrible situation, soon confirmed by MRI. Following a series of conversations with a neurologist and other colleagues, my own impression that this was an untreatable condition was confirmed. He was anticoagulated with heparin but in truth his only hope was that with the passing of time there might be some spontaneous improvement in his neurology.

Further examination that evening was a little more complicated than before because he seemed more withdrawn or sleepier, although he was clearly still able to respond.

During the course of that day, I had a series of conversations with Mr A's wife and sons in preparation for a more definitive meeting that night. During those discussions I asked about him and his family, his job, where they lived..a whole lot of questions to get a greater sense of both him and them as a family. It was also an opportunity to begin to talk to them about the horror of what had happened and the likely poor outcome. I remember them well, they appeared to be a very close family, intelligent and articulate.

For their convenience we arranged for a more definitive meeting to allow more family to attend. That eventually took place at midnight. There were 50 people in the room; Mr A's siblings, his cousins and their children and his wife's family too.

I had a number of goals for that meeting: to ensure that the family understood as best they could what had happened to Mr A and what our treatment plan was; it was important that they understood the seriousness of the situation and that although we would support him for a few days in the hope of a spontaneous improvement in his functionality, that this was likely to be a fatal condition. I explained that he had expressed a desire to be kept asleep apart from those times, twice a day, when we would wake him up to examine him. When that happened he would be wide awake and that apart from eye movements he could not communicate and I had no idea of what might be going through his mind; I asked the family whether they felt that he would want to be awake to spend time with them; were there things they needed to say to him and perhaps him to them; were there practical issues they needed to discuss or resolve, things like a will.

These were extraordinary people, (actually in my experience extraordinary might easily be replaced with ordinary)..they asked good questions and seemed to understand what I was saying. They asked me if they could think about the things we had discussed, especially the questions I had asked, and reconvene the next morning at 7am.

We did, this time with fewer family members and they had quite sensibly appointed a family spokesperson, to speak on their behalf. The mood was more formal than the previous night, friendly, warm but definitely more formal. The

young man was nervous and spoke from notes that he had carefully written out. He started by expressing the family's gratitude for the time that our staff had given them, the careful explanations of what had happened and our honesty in admitting that we couldn't really explain why it had happened. He talked about how confused the family had been, what a terrible state they had been in the night before and how helpful it was to hear my explanation and have a framework to order their thoughts. He then addressed the issues that I had raised one by one.

Later that morning the family spent several hours with Mr A whilst he was awake. The same the next day. During those times, I drifted past the room and occasionally caught the eye of his wife or one of the family..each time they gave me a genuinely warm smile. He didn't improve, in fact he became weaker and more drowsy. Several days later, with his family there, under heavy sedation he was removed from the ventilator and died.

A few days after that we received a card of thanks signed by the whole family. I look back on that with sadness but also with some satisfaction. There are some things you just cannot control, and all that you can do is make the best of what you can.

Second story:

At 0730 one Saturday morning, Mr B, a 61 year old man choked at home and went into cardiac arrest. His wife called an ambulance and started CPR. By the time the paramedics arrived 10 minutes later, he was already in asystole, his heart, the dumbest organ of them all, had not only stopped but was showing no electrical activity. The paramedics followed their well rehearsed protocol and eventually Mr B's heart started. It was 0800, thirty minutes after his collapse.

By the time he arrived at Middlemore's Emergency Department he was still deeply unconscious.

Things didn't look very good at all. He had had a long down time, so long that his heart had stopped. If this truly was the result of choking or asphyxia as we call it, and there was no reason to suspect otherwise, his brain would be well gone. His fixed and dilated pupils spoke to that. Following a brief discussion with his family he was transferred to the ICU for ongoing assessment and support.

Mr B was a coloured man from the United States and worked as a chartered accountant. Soon after arriving in NZ he became unwell and was diagnosed as with a weird auto immune disease that can affect many parts of the body.

Despite aggressive treatment for this disease he developed kidney failure and required dialysis. Eventually he received a kidney transplant.

Back in the ICU, at around 1230, five hours after his collapse at home, Mr B appeared to become Brain Dead. His blood pressure rose precipitously to 300mm of mercury. A few minutes later he stopped taking those gasping breaths and his blood pressure dropped just as precipitously to 60mm of mercury. This was something that I had witnessed many times before.

The family was in the room when all of that happened; Mr B's brain had continued to swell as a result of his cardiac arrest that morning. As a result of that swelling the pressure inside his skull rose to a point greater than his blood pressure, at which point his brain lost its blood supply causing those swings in his Blood pressure, and stopping his own spontaneous breathing.

I decided that later that day I would do a series of simple bedside clinical tests to determine whether or not Mr B was truly brain dead and speak to the donor transplant coordinator to see whether he might be eligible as a donor. Then I would talk to the family about their options.

Making a clinical diagnosis of brain death is a serious business and tightly regulated. All of us involved in this in Australasia, by that I mean the intensivists, transplant coordinators, anaesthetists and surgeons use the same set of guidelines. They are designed to deliver certainty, to ensure that we know the cause of the condition and to exclude confounding conditions that might mirror the findings of brain death.

They also serve to demonstrate the irreversible nature of the loss of brainstem function as they require a period of observation of the "brain dead" patient in the ICU.

Once that diagnosis is secure, in conversation with the family, a decision is made as to whether they wish to explore organ donation as an option. If they don't, again together with the family, we would find a suitable time when we would remove the patient from the ventilator. After a period of minutes, sometimes just a few, sometimes up to 15, the patient's heart would stop.

I completed the 2 sets of bedside tests and confirmed that Mr B was Brain Dead. As I was finishing up I noticed Mr B's right leg move, quite spontaneously and unassisted, it flicked inwards and fell back to where it was. I remember seeing this for the first time in the ICU at the London Hospital (now The Royal London) in Whitechapel in the mid 80's when I worked there as a registrar. A young woman in the same state after a severe asthma attack moved in a jerky fashion all over the bed. These are spinal reflexes uninhibited now due to the loss of higher neurological control.

Over the years I have spent a lot of time with families in this position – shattered by something sudden and out of their control. Mostly they are in such a state of shock they can't decide whether to sit up or sit down. They need compassion, deliberate and careful explanations of their options and they need time. They are the ones who will go on living and they are the ones for whom despite the tragedy, this can be either an experience that brings them together as a family or one that drives them apart.

When I finally came to speak to this family, I posed the following questions about organ donation as neutrally as I could.: Had Mr B expressed a view? Had the family ever talked about this? What do you think Mr B would have wanted? What can you live with? These are the issues they needed to consider and that if they were to go for organ donation, there will be an inevitable delay in order to complete the necessary tests; to mobilise the relevant retrieval teams; and to notify and prepare the recipients wherever they might be.

The family said yes to donation. Mr B had been a recipient of an organ, this is what he would have wanted and this is what the family wanted too. I thanked them for their consideration.

For me, and I explain this to families, it is the offer that counts, because sometimes despite a willingness to donate, it doesn't happen because of a range of reasons..things like the discovery of an undiagnosed viral infection in the donor, or there is no suitable match, or the organs just aren't right,

I rang the transplant coordinator, she contacted the liver team from Auckland and we settled on ten thirty pm for the retrieval to happen in the operating theatres at Middlemore. As it turned out, Mr B's liver would go by private jet to Melbourne.

Whilst all this was happening, Mr B began to move in the bed. That leg flick became more frequent and soon his left leg was moving. On one occasion both legs moved as though he was bending them up into his chest. Later on his head moved; his wife thought he was turning towards her. Mrs B and the adult children were really distressed by this and so was I. I had seen spinal reflexes before but not like this. These movements were really disconcerting.

Was he really brain dead, his wife asked? Was I sure that there was nothing else going on? Well I was sure but the human side of me was caving in; I began to worry about this.

As clear as things seemed before, I worried now about the original story. Did he really choke? Maybe he'd had a bleed. Why didn't we do a CT scan? Being certain of the diagnosis is on its own a prerequisite for donation. That he was brain dead, I was more certain. My rational scientific persona, my experience and that I had done the tests with great care reassured me, but I could tell now that Mrs B had her doubts. She looked absolutely tortured. I spoke with her and

the family. They thought that maybe he wasn't brain dead, they even wondered, hope springs eternal, that he could recover.

It was already nine o'clock; the liver team was due in an hour and a half. I rang the transplant coordinator and asked her to put them on hold. I rang my brother, an Intensivist at Auckland Hospital, like me also on call on that night, and I rang Stephen Streat, an Intensivist at Auckland too, but also the Medical Director of Organ Donation New Zealand. Together we made a plan.

I came back to Mrs B with what I thought was the right way to go. We'll take Mr B down and scan his brain first to see that the findings are consistent with asphyxia and cardiac arrest and then to demonstrate an absence of blood flow to his brain. Then we'll reconsider what we do on the basis of what we find. To say that she felt relieved by this is an understatement. I could see the weight gently lift off her shoulders.

The scan of his brain confirmed the original diagnosis: it was swollen and totally in keeping with what we would expect to see in such a circumstance. Further investigations showed his brain to be devoid of any blood flow. He was definitely brain dead.

I asked Mrs B and her children to reconsider their decision to donate. She said it was what he would want to have happened, but it was clear to me that she still had her doubts. I countered: the decision they made, either way, had to be something that she and the family could all live with. Over the next couple of hours we had a series of conversations. At 0100 she and the children called me in to say they had decided to go ahead with the donation and they were sure that this was the right thing for Mr B **and** for them.

At 0200 the liver team arrived. The family saw Mr B off as he was taken to the theatre. His liver, carefully removed, with all its plumbing attached didn't go to the airport but to Auckland Hospital instead.

Unbeknown to me, following our earlier conversation, my brother's night had become more complicated too. On that same Saturday morning at about the time that Mr B collapsed, a 40 year old woman was taken by her family to an emergency department at a small provincial hospital. She had 3 children and worked during the day looking after intellectually disabled adults. A few days before, she had been bitten by one of them. By the time she was seen in hospital she was deeply jaundiced and quite sick. She had acute hepatitis B infection and despite appropriate treatment, by late afternoon, had become increasingly unwell; her liver function was steadily deteriorating and her kidneys progressively failing. She and her family were flown to Auckland. By the time she was transferred to my brother's department she had fulminant liver failure and required a full course of intensive care support.

At about 0700 on Sunday morning, 24 hours after Mr B's collapse, she received his liver. It worked immediately and over the next few days her organ failure improved and she was transferred out of intensive care to a ward.

It is normal for transplant coordinators to make contact with the donor family to see how they are and offer support but also to let them know how the recipient is progressing. Mrs B was absolutely thrilled to hear this news.

Those first 2 stories are as real as they are dramatic but a much more common occurrence is illustrated in this next much shorter vignette.

Story number 3

Many people with significant chronic disease are on a downward spiral such that should they have an acute deterioration in their condition, it is unlikely that they will return to their previous level of function and many will not survive. Despite this, and perhaps because of the multiple care givers involved in looking after such patients, they are rarely asked their views on what they think should happen when this inevitability eventuates. What tends to happen, is that in the absence of a very clear signal, a patients signs and symptoms are treated rather than the whole person who exhibits them.

Mr C was an 80 year old Maori man, a retired farmer who had enjoyed the outdoors life. He'd had diabetes for years, chronic renal failure, severe chronic respiratory disease and congestive heart failure.

He had been an active man up until a year or 2 ago but more recently he had become increasingly confined to his house. He was admitted to hospital with cellulitis, a skin infection affecting his chronically swollen legs.

Early one morning, on a medical ward, he developed abdominal pain from a perforated ulcer. The House Surgeon who saw him didn't know him, the surgical registrar didn't either. A theatre was prepared and he was seen by an anaesthetic registrar. The medical machine was on a roll..its cogs were turning..slowly..but turning al the same..

The patient was not well, something that the anaesthetic registrar quickly picked up on. He thought that after the surgery Mr C would need intensive care..so he called us..it was 4 in the morning. Mr C's family had arrived on the ward at the same time as me.

I spent some time with them and the patient; talking about how he had been, trying to get a feel for what he thought should happen to him. It became clear to me that operating on this man was definitely the wrong thing to do..Mr C was already on a rapid downward spiral, one that he recognized and one that we could not influence. In the end he went home under the care of the palliative care service and died there 3 days later.

This leads me to the first of a series of observations on death

First to recognize the reasonableness and the extraordinariness of ordinary people

- We are lucky in NZ..our people are sensible and generally realistic in their expectations about what is possible and what they want for themselves and their loved ones. Quality of life and independence seem to me to be recurring themes in those conversations.
- These occasions when we clinicians, families and friends care for the dying are unique and moving experiences for everyone concerned.
- They are as emotionally harrowing as they are spiritually uplifting and a direct result of the inherent dignity and honour that most people exhibit when faced with such adversity.

• Although we all will die, **End of Life Planning** is not commonly done.. Intensive care staff like me are often called upon to make life and death decisions about desperately ill people, at short notice, usually in the middle of the night or early in the morning, without the benefit of knowing the patient or the family and without the kind of guidance or information we need to help us. Some of us manage this better than others. I try to share those difficulties by talking the issues through with the patient and their family, and given the chance, with their GP and my colleagues.

More proactive approaches to end of life planning are clearly needed.. Without that, it is likely that critical decisions about you will continue to be made without you, and that things might be done to you that you may not want.

As clinicians we should not be afraid to talk to the public about end of life issues, for many it is the elephant in the room.

A more structured approach to this is the Community based programme Respecting patient choices. Here, trained people initiate conversations with individuals known to be near the end of their lives..the very elderly and frail in rest homes and those identified as having near end stage or end stage organ failure. Conversations centre of what those people want for themselves when the inevitable happens and they have a significant deterioration in their condition. The overwhelming evidence is that these people are thrilled to be asked..why has it taken so long they wonder..the vast majority know they are at the end of their lives..they don't want to be tortured in hospital by 14 year olds, only to die there or be rendered more infirm... in addition to this, a richness of information

comes out: “if I am going to die, I want to die in my home; in my garden; I want this music playing; these people around me”.

These elderly and infirm people are then urged to discuss their choices with their families, document their wishes and make them known to their care givers, their GPs, the ambulance service and local hospitals. Such has been the success of this programme, in which their wishes are being followed, admissions to acute beds in hospital in this group have decreased and more resources have moved into community palliative care.

My advice to you is talk to your family and friends about what you want, talk to your GP, and specialist medical staff, document your wishes.

My penultimate observation is to recognize that the resilience and strength to deal with adversity and loss comes from our families and friends, our cultural and ethnic roots and our spiritual beliefs

Ironically, our community in south Auckland, a place of significant poverty and deprivation, has that resilience and strength in abundance.

At first glance the individuals accompanying many of our patients seem ill equipped to understand and participate the process of their relatives dying in the ICU. Those people are often able to access a wider whanau or community or cultural group that seems to uplift them and support them through and I suspect as a result of this family and community ties are strengthened.

And lastly

For me in particular, the reality of Death is a real motivation to live an enjoyable and full life.

A toast: To life and to absent frined