Disabled doctoring – how can we rehabilitate the medical profession?

Alan Clarke Memorial Lecture, 27th November 2008, at the Australian and New Zealand Spinal Cord Society Conference, Christchurch, New Zealand

Dr Robin Youngson
robin.youngson@waitematadhb.govt.nz

Biography

Dr Robin Youngson is a former engineer, a practising anaesthetist, a systems thinker, and for six years was Clinical Leader for the development of the new Waitakere Hospital in Auckland. Robin is the founder of the Centre for Compassion in Healthcare (www.compassioninhealthcare.org).

Robin graduated with an honours degree in engineering at Cambridge University. He worked for three years in oil exploration, saving funds to pay his way through medical school in Bristol. He took honours in Medicine and then became a Fellow of both the Royal College of Anaesthetists of England and the Australian and New Zealand College of Anaesthetists. He was the pioneering doctor on the ‘Childflight’, paediatric Air Ambulance Service in NZ. He started his first consultant job at Auckland Hospital as an anaesthetic specialist in 1994.

Robin was Acting Chair of the EpiQual committee in 2006 and played a significant role in shaping the NZ national strategy for quality improvement in healthcare. Until 2008 he was a member of the new national Quality Improvement Committee (QIC) and also the NZ representative on the International Steering Committee for Patient Safety Solutions within the WHO Global Alliance on Patient Safety.

He was also an international spokesman for the World Health Organisation in the launch of the new policy on “People at the Centre of Health Care” in November 2007.

Robin has presented widely on issues of clinical service redesign, patient-centred reform, clinical leadership, patient safety, open disclosure, and compassion in healthcare.
Disabled doctoring – how can we rehabilitate the medical profession?

Introduction:
Following in the footsteps of Alan Clarke, who was very determined in challenging autocratic models of medical professionalism, Robin reflects on his long journey back to humanity after the paralysing effects of medical training and professional traumatisation. For much of his career, Robin was blind to his profound disabilities as a doctor, although he was the master of technical excellence! If there is any rehabilitation to be done, it's the doctors who need to be brought back to life.

Our greatest teachers come and visit us every day, if only we would stop and listen. With stories and ideas that are stimulating a renewal of humanity and compassion in healthcare around the world, Robin introduces a host of characters that taught him the difference between providing a service and being of service.

Our patients are our greatest teachers
I begin with the story of Jessie, a memorable patient ….

She is a constant presence at my side and has been one of my greatest teachers. She taught me that sometimes it’s the role of the patient to look after the doctor.

When I first met Jessie, she was 85 years young.

She came to my anaesthetic clinic in a wheelchair, somehow looking crumpled and lopsided, having suffered a devastating stroke twenty years before. Her left side was completely paralysed and useless. From time to time, her useless arm would slide off her lap and dangle, withered and limp, over the side of the chair. She’d haul it back by reaching across with her right hand. She was rather overweight and the tissues of her face sagged in untidy folds like an unmade bed. She had only half a smile but there was mischief and light in her eyes.

Despite an appalling catalogue of medical complaints, she still managed to live alone and I quickly began to sense an indomitable spirit.

Jessie came to my pre-operative clinic because she had bowel cancer and her surgeon was fearful of submitting her to the perils of surgery, owing to her advanced age and so many complicating medical conditions.

In my hospital, I had created the very first anaesthesiology clinic and I wrote to all my surgical colleagues, inviting then to send me their ‘worst’ cases, those deemed too risky for major surgery. I promised I would do my best to assess and predict the level of risk involved in surgery/anaesthesia and to help patients come to a decision about whether the risk of surgery outweighed the potential benefits.

Some of the patients were sent to me because the surgeons wanted someone else to give the patients the bad news.

I took my job, and myself, very seriously.

Jessie was quite the ‘worst’ patient that ever came to my clinic. It took me a long time to summarise all the information from her bulky hospital charts, to enquire into her current symptoms and to perform a physical examination.

She was in big trouble. Her bowel cancer was continually bleeding and she was becoming severely anaemic. The tumour was causing obstruction and it was hard for her to eat. The
colicky abdominal pains were troublesome. In addition to her massive stroke, Jessie had a long list of serious medical complaints. She had complicated and severe heart disease. Her main heart valve was almost petrified and severely narrowed. Her coronary arteries were clogged. She teetered continuously on the edge of a heart attack and suffered frequent attacks of anginal chest pain. Her severe anaemia greatly exacerbated her cardiac condition and she was breathless with a build-up of fluid in her lungs. She had diabetes, high blood pressure, raised cholesterol and damaged kidneys. She took eleven different medications.

My report to the surgeon spanned three pages. I concluded that Jessie had only a fifty-percent chance of surviving her operation and that her prospects of ever leaving hospital were dismal. There was very little we could do to improve her condition although correction of her anaemia with a blood transfusion would reduce the cardiac risk.

With a heavy heart, I did my best to explain to Jessie the enormity of the surgical risk.

‘What’s the alternative?’ she asked.

‘If you don’t have surgery, the blockage in your bowel will get worse, the bleeding will continue, and you will probably die of heart failure and bowel obstruction.’

‘Is there any other form of treatment for the bowel cancer?’

‘No,’ I replied, shaking my head. ‘We would do our best to keep you comfortable.’

‘Well, I really don’t have a choice, then…. Robin, I want you to take on my case, I want you to do my surgery. I’ll take my chance. I’ve had a good life and if I die having surgery then it’s not anyone’s fault. I won’t blame you!’

I then began to explain to Jessie that we could reduce the risk of her surgery if we gave her a blood transfusion. ‘Jessie, we need to give you a blood transfusion to take some of the strain off your heart. Because of the bleeding in your bowel, you have become very anaemic and your blood count is down to 82. It should be about 130. With your blood so thin, it doesn’t carry enough oxygen so the heart has to work very hard to pump extra blood around the body. Also, the heart muscle itself isn’t getting enough oxygen to sustain that extra workload. That’s why your heart failure is getting worse and why you’re getting angina so often.’

Jessie then smiled sweetly and told me she would not be having a blood transfusion! She must have seen the expression of dismay on my face. ‘Robin, I’m a Jehovah’s Witness and my religion does not permit blood transfusion. I understand that increases the risk but I would rather die and go to Heaven than survive and be damned. I’m sorry it makes it more difficult for you but I’ll just have to take my chances.’

In a moving gesture, she took my hand in hers. ‘Robin, I put my faith in you. I know you’ll do the best job you can and God will be watching over you.’

This was getting very personal! Clinical detachment was at threat here. Not only was she addressing me by my first name, but she was holding my hand and invoking her God to watch over me. Next she’d be asking me to join her in prayer!

My next clinic patient was waiting. I told Jessie that I would write to her surgeon recommending surgery, even though the risk was very high. She thanked me for my time. As I called in the next patient, I sincerely hoped that the awful challenge of giving an anaesthetic to Jessie would fall to one of my anaesthetic colleagues.

A note of explanation is probably warranted here. Many people assume that the role of the anaesthetist is merely to put the patient off to sleep at the beginning of the case and to wake up the patient at the end. This is a gross oversimplification. During complex surgery, the
surgeon is fully occupied with the technicalities of the procedure and doesn’t have an overview of the patient’s condition. Surgery can be a major stress to the human body, causing profound changes in physiology, altered organ function, major blood loss, and so on. It’s the job of the anaesthetist to keep the patient safe and alive during surgery. In a case like Jessie that involves very sophisticated intensive care and life-support measures finely adjusted for each moment of the surgery. This is a ‘knife-edge’ balancing act where the slightest error can result in a downward spiral of deteriorating organ function, falling blood pressure and cardiac arrest. This may be the end result, even without error. Hence, my heartfelt wish that someone else would face this sobering responsibility.

However, fate had determined this would be a very personal lesson for me. On the eve of surgery, I discovered to my dismay that I was allocated to the operating theatre where Jessie would have her operation.

With a heavy heart I went to consult with her on the ward. I felt duty bound to explain again the dire risks she was facing. Informed consent is a mainstay of professional practice. I do wonder, sometimes, whether it’s really in the patient’s best interest to half frighten them to death before major surgery?

Jessie cut me off short. ‘Robin, we’ve discussed all that already. I understand the risks I’m taking but I put my faith in you. I know you will do the best you can.’

She held my hand again. This was disconcerting. She said to me, ‘Robin, you’re looking so worried about giving my anaesthetic that I think I need to cheer you up. I’m going to tell you a joke!’

Now, bearing in mind this was an eight-five year old lady, half paralysed in a wheelchair, and facing almost certain death in the next few days, the joke she told was magnificently bizarre and ridiculous.

Lifting her forefinger up to touch her lips, she blew a lopsided and wet sounding raspberry. ‘What’s that?’ she said!

‘I have no idea,’ I replied, shaking my head in confusion and disbelief.

‘It’s a fart trying to get past a g-string!’ she said with a wicked twinkle in her eye.

I was now completely undone. Any semblance of the proper doctor-patient relationship had now dissolved in helpless mirth.

When the tears were wiped away, I revised my estimate of her chances of survival. This was a human spirit not yet ready to depart the world.

We made our farewell and to my surprise I was able to put aside my fretful worrying to sleep soundly in preparation for the next day’s challenge.

Jessie had a stormy time in surgery and post-operative care. She narrowly scraped through several crises, never once complaining. I went to see her again, three days after surgery when she was back on the ward.

She held my hand again. ‘Robin, I prayed that you would survive my anaesthetic, and you did!’

Those events took place ten years ago. Jessie has since passed on but she is always at my side. Often, when I speak at conferences or workshops, I will start my presentation with that story. I put an empty chair beside mine to signal her presence.
Jessie had a lot of lessons for me to share with the rest of the world. At the time, I wasn’t open enough to learn all of the things she had to teach. But hardly a day goes by when I don’t reflect on her inspiring example and challenge myself to match her incredible compassion and courage.

Over the years I have begun to understand some of her lessons.

*The first lesson was that of simple humanity.*

Jessie, with devastating effectiveness, undid all of my defences and gave me an experience of shared humanity. She used one of the most powerful tools at our disposal – humour and laughter. It was the start of my journey of personal healing. It’s something I teach a lot to my colleagues, the stepping aside from professional and expert roles for a moment to simply be a caring human being.

*The second lesson from Jessie was one of interconnection and interdependence.*

Before Jessie, I conceived of the doctor-patient relationship as a one way street. I was the highly trained doctor, the expert, the person with authority and control. Caring was a one-way process. I cared for patients and I determined the process and the agenda. Patients didn’t care for me. They were grateful, of course, they took my advice and they did what I told them. Those who didn’t were “difficult patients” or “non-compliant” or “manipulative”.

But somehow, Jessie turned the tables on me. She was the one caring for me and supporting me in my difficulties. The relationship had become a two-way process.

*The third lesson from Jessie was about choosing an attitude.*

In the face of severe disability and pain and the prospect of almost certain death over the next few days or weeks, she chose her attitude. She wasn’t grumpy or ill tempered. She didn’t complain. She didn’t dwell on her misfortune. She chose instead to show concern and compassion for me as a vulnerable human being. She gave me support, she cheered me up, she told me a joke!

If Jessie could choose humour and laughter and compassion in her awful circumstances, then what excuse have we ever to do less ourselves?

Attitude is highly contagious. And attitude exists at many different levels, from the individual, through the team, to the whole organisation. We sense it the moment we walk into a place like a hospital.

*The last lesson that Jessie taught was that laughter is the best medicine.*

No matter how dire the circumstances, there is a place for gentle humour and even a good belly laugh. If we can learn to laugh at ourselves then we open up our hearts to a deeper human connection and the humility to learn. Laughter is a wonderful release for tension and anger. A workplace that creates fun and humour through the daily challenges is a more joyful, creative and energising place to work.

These four lessons, simple humanity, interdependence, choosing an attitude and laughter are a wonderful prescription for the beginning of personal transformation and developing open hearted compassion.

*A personal connection to spinal injury*

Four years ago my eighteen-year-old daughter Chloe had a serious road accident and she broke her neck at the C1/C2 level. Her complex fractures were managed conservatively so
she was confined to a hospital bed for three months, in spinal traction. Her care was provided in a major hospital where I had worked as a medical specialist and also a member of the senior management team. If anyone could ensure that Chloe obtained the best care, it was me.

Chloe lay flat on her back with her head completely immobilised. She could see only the ceiling. She couldn’t see out of the window, she couldn’t see people who came into the room, she couldn’t watch TV or read a book, and she couldn’t wash or feed herself. Her dignity and independence, and her emotional and psychological needs were grossly neglected.

Meal trays would be brought into the room, put down out of her sight and reach, and then taken away again untouched. There were many caring and kind staff members but they were overworked. The overall system showed a callous disregard for her emotional and psychological wellbeing. Simple physical needs were neglected. Despite repeated pleas from our family, almost no aids were provided to relieve her disability or to maintain her dignity.

Eventually, I myself designed and built all her disability aids and installed them in the hospital room. She had a laptop computer mounted on the bed frame, where she could see the screen and use the keyboard. We arranged an Internet connection so she could surf the web and communicate with email. A web-cam on her bed showed her the view out of the window or the faces of people coming into the room. She could watch movies and listen to talking books. She used graphics software to do creative work. I constructed an upside down shelf to hold books or magazines. My wife, Meredith, and family and friends created a daily roster to ensure she had nourishing and tasty food. Our family spent more than $1000 on hospital car parking for the privilege of ensuring our daughter didn’t starve to death.

At first we thought that the neglect was a simple matter of oversight in a busy and understaffed ward but, as time went on, our feelings turned to anger and disbelief as we realised that the system was incapable of responding to Chloe’s basic human needs. We were a privileged family and I had considerable power and influence in the system but my feeling of impotence was profound. When the survival of a loved one depends on maintaining the goodwill of carers, one is very circumspect about raising concerns or complaints. We felt fearful for the wellbeing of other less privileged patients.

I’m glad to report that Chloe made a full recovery and that, seven days after her bonds were severed, she walked unaided out of the hospital – a remarkable feat after three months flat on her back. Chloe shared with Alan Clarke a blatant disregard of the limitations placed on her by well-meaning health professionals.

Following that awful experience we learned a lot about the complaints system from the wrong side of the fence. I have come to know the Health and Disability Commissioner as a close colleague and friend. He is an outstanding leader in the campaign to improve patient care but his powers needs to be strengthened by amending the HDC Code of Rights to include “the right to be treated with compassion”. It seems that dignity and respect are not enough. In a recent report on the death of a patient at Wellington Hospital the Commissioner noted multiple system failures. In the end, however, the greatest moral failure was the failure to respond at all to the suffering of a dying patient. “Where was the compassion?” said the Commissioner.¹ I have begun a personal campaign to amend the Code of Rights in NZ.

But in any tale of human suffering there are always inspiring moments to be cherished. In the case of my daughter Chloe, my wife and I will always remember the individual professionals who through their actions showed just how much they did care. The ambulance officer, who tended to my daughter for the long period she lay trapped in the wreckage, stayed behind at the hospital to meet the distressed parents in the waiting room of the trauma unit. She hugged us and told us that our injured daughter was not left alone. When I think of that simple act, I am completely undone. The transit nurses in the hospital took such exquisite care of our daughter during her complex journey of trauma assessment, to CT scans and so
forth. When they wheeled her on the trolley, they stopped at every single join the in the carpet to carefully lift each wheel over the bump and not cause further pain by jolting her fractures.

Our nightmare as parents lasted just a brief few months. For many of you this is a lifelong sentence. So I’d like to share with you my learning about just how much we need to challenge the concept of medical professionalism, to be able to serve those who have permanent injury.

**Losing compassion**

I began my professional life very far distant from the ideas and concepts I now present. In my first brief career as an engineer, I was the role model for rational and deterministic thinking. My chosen hospital speciality is anaesthesiology. You could not imagine a more rational, black-hat thinker, thoroughly versed in the culture, beliefs and assumptions of a highly trained, technical specialist working in a large teaching hospital. In my everyday work, most of the patients I met were transformed from a human being to a mere ‘physiological preparation’ during the course of an anaesthetic. I could inject drugs, adjust the anaesthetic and watch all the number change on the monitors. I chose a speciality where I didn’t have to talk to patients or conduct outpatient clinics. A background in engineering was a great preparation for this technical work.

It has been for me a long journey of profound personal learning from detached clinical specialist to humanistic practitioner, through a vehicle called compassion. The definition of compassion I most like comes from the WordReference.com English Dictionary:

*Compassion is the humane quality of understanding the suffering of others and wanting to do something about it.*

That’s a hard quality to sustain within our hospitals. I think we have evolved systems in which we really don’t give people permission to care. Here’s a simple litmus test: If a nurse in a busy ER was to sit attentively on the bed of an elderly patient, hold her hand and just quietly listen to the real concerns of the patient, how would the system respond? In most places I have worked, there would be swift censure. How did we lose caring and compassion when these are the core values and motives that brought health professionals into their careers in the first place?

**The brutalising effects of medical training**

I think we are brutal in the training of health professionals. As a mature student, medical school was a distressing experience for me. I saw many inhumane things done to patients in the name of medical practice and I’m not sure it has changed very much in the intervening twenty years. On my first weekend on duty as a junior doctor, six of my patients died. I was not permitted to cry. I was also not permitted to sleep for nearly three days. I went to work on the Saturday morning a sane human being and returned home on Monday evening weeping uncontrollably. These are not isolated incidents but a repeated pattern that betrays the inhuman culture of medical training. More recently, as an anaesthetic trainee in Auckland, I was to witness the sudden death of three young patients in one afternoon but I was expected to continue my fourteen hour shift as if nothing had happened. I vividly remember going to my next patient and silently wondering if telling him that my last three patients had died was a requirement of informed consent!

The end result of this brutalisation is a retreat away from humanity and the evolution of systems of practice where the experience of the patient is often that of a callous system, unresponsive to their feelings and needs, despite the good intentions of those who work within them. That state of affairs is commonplace as anyone will know who has been helplessly dependent as a patient in the system.
Wrong thinking

I think the problem really began in the Age of Enlightenment, the time of Newton and Voltaire and “the triumph of the intellect over base emotion”. That time was the major genesis of Western thinking about the nature of the universe and theories of knowledge. From Newtonian mechanics comes a clockwork analogy of the world, a deterministic view in which understanding of the parts led to prediction about the function of the whole. Medicine has adopted an increasingly fragmented, mechanistic and detached view of the patient. Clinical detachment and objectivity are core values in medical practice. There is little room for understanding of complexity or interdependence. When doctors deny their own humanity, patients suffer and so in turn do the doctors.

I believe much of compassion is lost through fear and defensiveness. In the anxiety-provoking world of early clinical practice, when we are so lacking in confidence, we adopt this detached clinical role as a defence against our own feelings of inadequacy. In the face of tragedy, we retreat to a place of supposed emotional detachment and formalised doctor-patient relationships. As time passes, we become wrapped up in a notion of professional identity and self esteem which I call ‘expert professionalism’. Like a player on the stage, we become skilled at using the uniform, the symbols and props of our profession to maintain that distance and to exert power and control. It’s a vulnerable place to inhabit because the very foundation of underlying beliefs and assumptions is deeply flawed.

One challenge to these unquestioned assumptions about objectivity and clinical detachment comes from a strange place. Daniel Goleman is the best-selling author and leading psychologist who has researched and popularised the concept of emotional intelligence. Goleman is increasingly interested in cross-cultural concepts and the fusion of Western neuroscience with ancient traditions. In 2000, he attended a week long retreat in Dharmsala with the Dalai Lama, with leading edge Western psychologists and neuroscientists, and Tibetan lamas. It’s a fascinating, cross-cultural dialogue and exploration. Goleman describes the dialogue in one of his recent books, “Destructive Emotions”.

An early difficulty in dialogue was that it proved impossible to translate the word “emotion” into Tibetan. The Buddhists had no concept of emotion as separate from cognition and there was no Tibetan word equivalent to “emotion”. In the ancient Buddhist tradition, there are many mental states but all of them combine the elements of cognition and emotion as an inseparable whole. Negative mental states such as anger, anxiety or “attachment” are described as obscuring or affiliative mental factors that distort and cloud perception. According to Buddhist tradition, the only mental state in which the subject can accurately perceive the world is open-hearted compassion. This notion contrasts strongly with the Western theory of “clinical detachment”. During the dialogue, leading Western neuroscientists reported the latest studies on brain function. Functional MRI scanners now allow us to see the brain working in real time. The activation of cognitive and emotional centres can be seen on the scans. No instance of cognitive activity could be found without a corresponding activation of the emotional centres. Emotion and cognition are two sides of the same coin. Patients with brain injury in the emotional centres are unable to make rational decisions. Emotion is essential to the process of applying intuition, wisdom and judgement to make apparently “rational” decisions. Rational detachment may be a Western delusion.

Clinical detachment as a defensive mechanism is therefore profoundly flawed. Every patient injury is a wound in the doctor’s heart also. The effect is to exacerbate deeply held fears and the sense of personal inadequacy, starting a vicious cycle that is profoundly dehumanising. The wonderful discovery is that open-hearted compassion can reverse that process and lead practitioners back to humanity and personal healing.

One of the barriers to caring is an assumption that compassion is a one-way street and that giving our empathy and compassion to every patient would drain our resources and lead to
burnout. You will have a sense from my stories that my experience has been different. In the Buddhist culture, each act of compassion is perceived equally to be an act of compassion for the giver as much as the receiver. My experience has been that the more compassion and loving-kindness I give, the greater is the store of love in my heart. When we “practise” compassion we strengthen and grow the parts of the brain concerned with positive emotions.

The consequence for our patients of expert professionalism
I use the word “patient” deliberately, with all its negative connotations, because much of the power imbalance between professional and subject of care lies in the assumption of roles. For most of my career, I have been completely unconscious of the power I held over patients, in my assumed role as technical expert.

The rise of ‘expert professionalism’ has made physicians fearful of failure. My own chosen profession is anaesthesia. For many years, the source of my professional self-esteem was expert knowledge and technical skill. My patients expected me to be infallible in judgement, error-free in execution and to have technical solutions for all their problems. When my patients were harmed through error or presented problems that couldn’t be fixed, I faced double jeopardy: the awful failure of my professional purpose and inability to provide the personal support, compassion, and caring that would have led to shared healing. Lacking the interpersonal skills and confidence to care as a simple human being, I shunned the broken patient. I believed there was nothing more that I could do. Personally identifying with the traumatic loss of the patient was just too threatening. Much of the vulnerability of physicians arises from this model of expert professionalism.

Out of this paralysing fear arises the need to control the agenda. As a doctor I was always friendly and helpful but I was certainly the person in charge. If my patients brought up other concerns or questions, beyond the scope of my technical expertise, I was skilled at diverting them back onto safer ground.

I have a compelling image in my mind that I cannot shift because it so powerfully symbolises the nature of my past practice. I’d like you to imagine the pioneering railway gangs laying tracks into the wilderness in the early days of the USA. They had a machine running at the head of the rails, which lifted a section of rail track from the wagon behind and laid it on the ground ahead, ran forward, laid the next section, and so on. That is how I see my past clinical practice. I was the one to set the agenda, I had a single track purpose that I relentlessly followed regardless of what was important for the patient.

Actually I knew about this problem in theory long before I recognised the behaviour in myself.

A research programme in Auckland attempted to improve the care of elderly patients with multiple medical problems, by integrating all the information about these patients held by their various health professionals and creating a single care plan for each patient. Each patient wrote a detailed self-assessment of his or her various medical problems and was asked what one thing could be improved that would really make a difference to their health or wellbeing. The patient goals were modest and achievable – not “cure my arthritis”, but “if you could improve my mobility a bit, I could get into the garden and that would transform my life”.

For each patient, the multidisciplinary team met to develop an integrated care plan that would be shared with the patient. However, the outcomes of the research were as unexpected as they were dismal:

- Only 52% of the problems considered most important by patients were discussed at the planning meeting by the health professionals.
- Only 35% of the problems considered most important by patients were included in the planned interventions.
- Only 14% of the problems considered most important by patients were actually addressed in the implementation of the care plan.
Research in the US examining the primary care of elderly patients produced strikingly similar results.\(^5\) 45% of patients over 70 have severe physical limitation and, of those, 80% said their doctor was aware of the problem, 50% remembered that the doctor had treated it and only 15% indicated they were much better as a result.

The truth is, health professionals rarely allow patients or clients to set the agenda. A study in Canada and the US examined audio recordings of 264 interviews between patients and experienced family physicians.\(^6\) Physicians solicited patients’ concerns in only 75% of cases. Patients completed their statement of concern in only 28% of the interviews because physicians redirected patients’ opening statements after a mean of 23 seconds.

I am being very blunt when I say it is the doctors who need rehabilitation, not the patients, but having survived rehab myself I feel qualified to comment.

Addressing this power imbalance between patients and health professionals was perhaps the most relentless passion for Alan Clarke and led to some of his greatest achievements.

**Deepening practice**

I have to confess that in the last ten years I have had to unlearn much that I was taught in medical training and about my role as a doctor. These insights are important for two reasons. Firstly, they illustrate the limitations of the medical model and, secondly, they show just how much we limit our own power by the prison of our perceptions and assumptions. It’s ultimately a tale of joy and liberation, which I hope might inspire the leaders in this room to seize power from within and transform our healthcare system.

My first story is about the sometimes-fractured relationship between midwives and hospital specialists. Here are two groups with profoundly different philosophies and experiences. The midwives come with a strong belief in childbirth as a natural process for which there should be minimal medical intervention. The hospital specialists see only the clinical crises and have to respond swiftly to life threatening emergencies. There is a natural tension between the values and beliefs of these two groups of professionals. It’s a microcosm of wider issues including the ‘medicalisation’ of disability.

As I write these words, I am sitting in my hospital on a Tuesday afternoon, on duty for calls to the maternity unit. I am the on-call anaesthetist doing epidurals for pain-relief in labour and providing anaesthesia for emergency Caesarean sections or other medical procedures.

I work a 24-hour shift. Childbirth is not an office-hours business. Sometimes I’m called out several times in the night, becoming fatigued and sleep-deprived. In those circumstances, it’s only natural to feel somewhat grumpy and sorry for yourself. I used to carry my grumpiness into work with me and be intolerant of frustrations, delays or missing equipment. I didn’t always experience the friendliest of receptions when I entered the labour room. Sometimes it felt like I was the enemy, the ‘wicked’ doctor come to intervene in childbirth when the plan was for a natural process with no drugs and no technology. It was an uphill struggle to find the necessary equipment, to ask the midwife to get the mother positioned for the epidural, and to communicate instructions. Sometimes the epidural didn’t work well and I’d be called out of bed again. I was overwhelmed with negative thoughts, tired and grumpy.

One day I decided to choose a different attitude – I finally learned the lesson from Jessie.

I chose to put different thoughts in my head. Now, when I’m called out in the middle of the night I think about the extraordinary privilege of being invited to take part in an intimate and life-changing event. I take great care with the spirit and presence I bring into the room. I enter the room with gentleness and compassion. I notice the effect this has on the mother in reducing fear and distress. I greet and acknowledge the other people in the room. I ask after...
the midwife, enquire whether she has been busy or had any sleep or rest. I do the epidural
with the minimum of fuss and then witness the miracle of pain relief. It is a joyous
experience. I don’t care how tired I am. I go home with love and joy in my heart.

How amazingly the world changed when I chose to have a different attitude! I used
sometimes to think that the midwives resented my coming to do an epidural. They were
sometime surly and uncommunicative, they would neglect to introduce me to the mother or
other family members in the room, I would have to ask for assistance, the equipment
wouldn’t be ready. Now I feel like an honoured visitor. I am greeted warmly. I have the sense
that my praises have been sung to the mother even before I step into the labour room. An
extra special effort will be made to anticipate what I need to make preparation for the
procedure. I find that my pain relief is much more effective and the rate of complications is
greatly reduced.

For most of my career, I considered the problem of the relationship with midwives as a
problem, “out there”. My more recent experience leads me to believe that the problem and
certainly the solution existed in my own head. The only person who changed was me but the
consequence of that was a remarkable change in my whole world experience.

Sometimes you have to change “me” to change the world.

As my practice deepened I began to reflect on my role, how I might best serve my patients
and where I might find the sources of the deepest satisfaction and joy. Over time, I have
gradually re-conceptualised my role as that of a caring human being first, and an expert
second. That enabled me to be much more humble and respectful, to listen patiently, to form
more trusting relationship with my patients and to bring much greater compassion and
humanity to the relationship. I began to take great pleasure in helping patients in whatever
way I could, regardless of whether it related to my specific technical role as an anaesthetic
specialist.

One day, I decided that I would no longer have ‘difficult’ patients. I decided that difficult
patients didn’t exist “out there” but were a consequence of my attitudes or judgement, an
internal problem. I decided that if a patient continued to make demands, or to break rules, or
otherwise be disruptive, it was a matter of my failing to understand or meet some need. I
owned the problem as my own, rather than projecting it out onto the patient. This had an
interesting effect.

Most of the ‘difficult’ patients had a long and chequered history of interaction with healthcare
services. They had often been treated with a lack of compassion or respect and had even on
occasion been punished by health professionals for what was interpreted as manipulative
behaviour. A classic example is the patient with chronic pain admitted to an acute care
setting. Often their behaviour is interpreted as “drug seeking”.

When I changed my attitude, I noticed an immediate effect. Often the patients were surprised
or taken aback. They were quite unused to doctors treating them with respect. I found it was
easy to negotiate solutions for particular problems with a bit of give-and-take on both sides. I
often act as an advocate for the patient but it is usually a small matter of negotiating
agreement with the rest of the staff, for instance to allow the patient to leave the ward to go
for a smoke. Quite suddenly I found I didn’t have difficult patients any more. This was
definitely an improvement in the quality of my working day! But paradoxically, the only person
who changed was me.

**Being of service**

I was so encouraged with the positive results of this experiment that I decided to extend it to
all my patients. I decided to take the attitude that no patient of mine made unreasonable
demands and I would simply do my best to respond to every matter brought to my attention. I
would be very attentive, I would try not to judge, I would be careful in the use of power, I
would let the patient set the agenda and I would continually seek permission and approval for
the process we were following together. My role came to resemble that of a coach or mentor,
rather than expert. That important shift required me to reflect on the great power imbalance
that existed between the doctor and patients.

My colleagues thought I was completely mad. It was obvious to them that I would soon be
overwhelmed, exhausted and burnt out. In their experience, patients continually made
demands that couldn’t be met and they had to employ a variety of means to defend
themselves against this unreasonable onslaught.

My experience was of completely the opposite effect. The demands of my patients grew less,
not more. In this paradox lies a clue to solving the problem of overwhelming demand on our
healthcare services.

The key insight is that there is a difference between ‘fixing’, ‘helping’ and ‘serving’. Fixing is
often the appropriate course of action for an acute condition or injury, or where chronic
disability can be reversed through technology such as hip joint replacement. Fixing puts the
expert in charge but that’s fine for the right kind of problem. The patient has a short-term
contract: I put myself in your hands for the sake of achieving this specific improvement. It’s a
transactional relationship.

Of course, many of the chronic problems we see don’t have a technical solution and they
can’t be fixed. While, on the surface ‘helping’ seems a laudable approach, we should be
mindful of the resulting power relationship. The helper is always in a position of power over
the person being helped. It’s a dependent relationship that takes power away from patients.
They take less responsibility for their own health and wellbeing because it’s the doctor’s job
to fix the problem. I’m unhappy, so give me a pill. I’m overweight so treat my hypertension
and diabetes. I’ve ruined my coronary arteries through unhealthy lifestyles so give me a heart
bypass operation – now!

As long as the doctor is stuck in the ‘helper’ mode, demand will be unrelenting. In the end,
chronic helping and rescuing diminishes patients, it makes them less capable of dealing with
their own life problems.

So why is my experience different? I choose to serve my patients on their own terms. You
can tell when someone is truly being served because you witness personal growth. The
person being served takes greater responsibility for their own health and wellbeing. Their
capacity for dealing with life’s challenges is enhanced by your coaching and support. The
relationship is one of deep mutual respect, honesty and openness. In this circumstance, no
patient makes unreasonable demands. The workload for the doctor decreases not increases.
However the joy and satisfaction in work is greatly enhanced.

It become a privilege to be invited to participate in intimate life events and to witness the
extraordinary courage and generosity of ordinary people as they struggle with this thing
called “life”. I certainly take delight in seeing their growing capacity for effective and wise
responses to life’s challenges.

Now I have learned to be still and to listen. Sometimes, quiet presence without anxiety is the
most profound intervention. Brokenness is part of the shared human condition. We do not
need to fix it or hide it, just be present and share our common experience of humanity. Often
I give assistance to patients, which is unrelated to my area of professional expertise. I
respond to their concerns and anxieties by helping them navigate the complex healthcare
system and to find some other source of support. My outpatient clinics don’t take any longer
but I just get to the heart of the matter more quickly and help patients develop their own
capacity for dealing with life challenges. They know that I care deeply, they are strengthened
by that knowledge, and they go away satisfied.
To step aside from the expert role and to bring the quality of compassionate, non-anxious presence requires a deal of inner work. Humility and non-judgement are important qualities. But how else could we expect to lead our patients through a process of self-reflection, healing and lasting change that only the patients can do for themselves?

I never met Alan Clarke and I find that surprising given our shared passions. I think we would have got on famously and I hope he enjoyed my presentation! It’s been an enormous honour to speak in his memory.

References

4 Mahoney F. Older people as the centre of the care and services. Presentation to CLANZ/NZIHM Conference, Auckland, 16 November 2001.