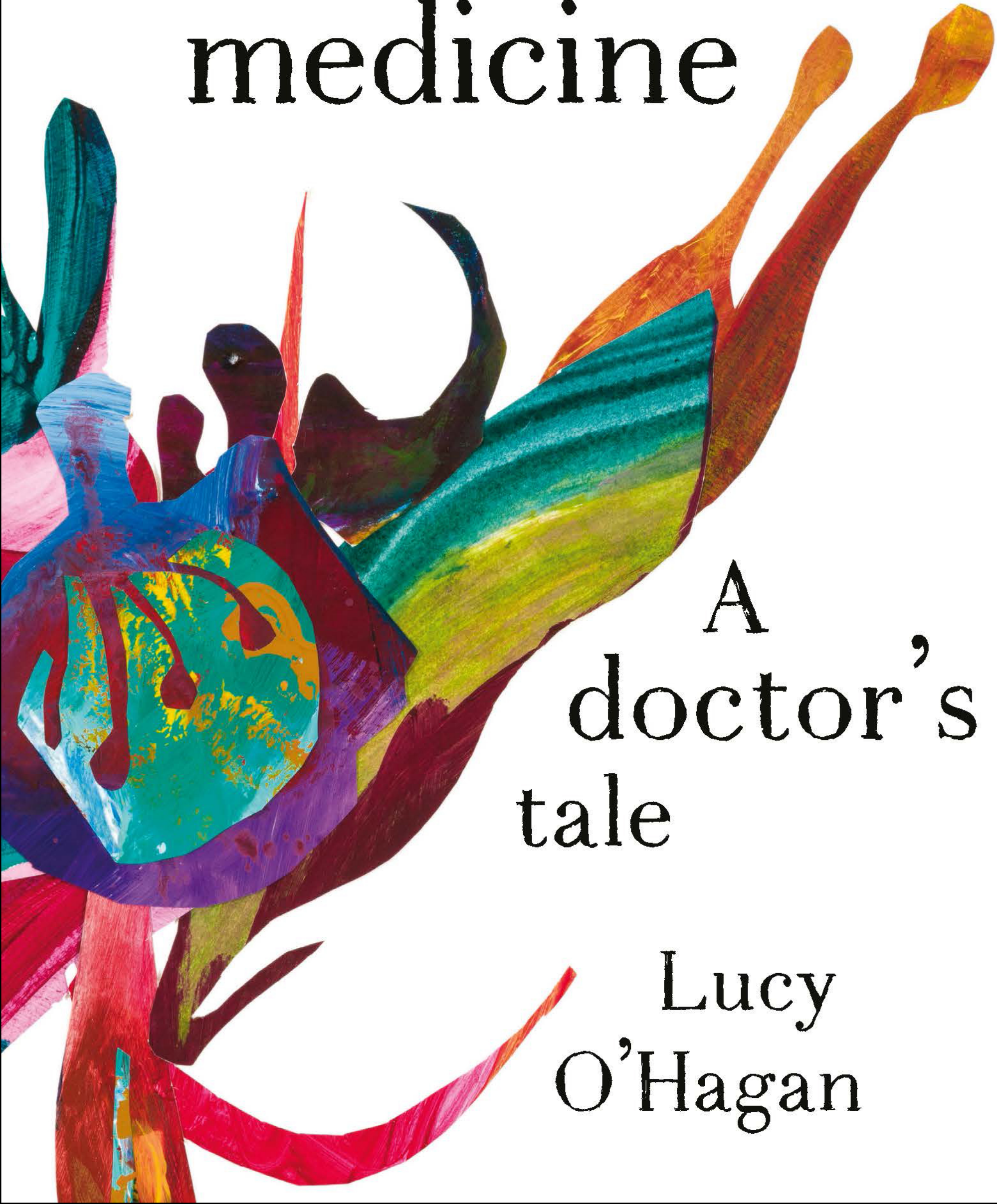
Everything but the medicine

A doctor's tale

Lucy O'Hagan



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Nō Aerani ōku tīpuna.
Ka tū ahau i raro i te maru o Tititea
i te tahataha o Mata-Au
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Ko tēnei taku mihi ki ngā tangata whenua o
  Te Waipounamu, me te motu o Aotearoa.
Ko Lucy O'Hagan tōku ingoa.
Nō reira tēnā koutou, tēnā koutou katoa.

My ancestors come from Ireland.
I stand in the shelter of Mount Aspiring
on the banks of the Clutha River
and on the shores of Lake Hāwea.
I acknowledge the tangata whenua of the
  South Island and all of New Zealand.
My name is Lucy O'Hagan.
Welcome, to all of you.

Who is the doctor writing this book?

A doctor's tale

A long time ago a young maiden with hairy legs and a love of stories went where few women had gone before: medical school. She wanted to help people, but the hallowed halls were daunting. The portraits of the deans, austere men, stared down at her as if to say: 'You cannot be a doctor and a mother. Begone.'

Learning to help people seemed to be a brutal process and she wasn't so sure about the type of doctor they were turning her into, but in the back row she met a gentle young man with a brown ponytail who liked to protest outside Miss New Zealand contests and to go to men's groups to talk about feelings, and there beneath a slide showing the embryology of the gubernaculum testis Hunteri, they fell in love.

They learned to be doctors together, although it was a long time before either of them dressed like a doctor. They were later taught by a wise but humble physician who believed that being human was as important as being clever, and with their newfound skills they went to a small mountain town in the southern island, where they met another doctor, a woman with sturdy boots, who proclaimed in her loud American accent, 'I am strong, I am invincible, I am woman doctor. I am as good as those boy doctors. I will open my own medical centre.' She put up her sign and consulted patients in a sleepout behind an old cottage.

And the local people asked, 'Are you a real medical centre?'

And 'Does your doctor write prescriptions?'

And 'Can your doctor stitch up a cut knee?'

To their amazement she did it all, and before long there were queues of people outside the door.

Soon after, the young woman with hairy legs joined her, setting up her consulting room out the back door and down a path in the former garage, which had been given a flick of fresh paint, a new door and some easy-clean linoleum.

And soon the young man, who had grown into a gallant young doctor, joined the two women, and he did manly things like writing prescriptions and stitching up knees, but he also had a way with laughter that could ease the lowest of spirits, and he became famous for performing magic tricks for unwell kids.

Eventually they ran out of sheds, so they found a larger house with enough rooms for all their doctors and nurses. They were very prudent with money so they sewed their own curtains and made desks out of old doors held up with bits of four-by-two.

And they employed lovely receptionists, of all ages, who dressed more like doctors than they did, which was reassuring for the patients, and through thick and thin, day after chaotic day, those lovely receptionists sat at the desk made of a door, smiling and being welcoming and making appointments in a big green book using a pencil, with an eraser nearby in case there were cancellations.

And they also had nurses, who were not tea-making handmaidens; oh no, they were modern nurses, who had opinions and did pap smears, and managed the whole outfit, so that everything was ready and nothing had expired and things worked seamlessly.

Then they got managers, and the managers knew how to put numbers in a wide black book called *Cash Flow* with different-coloured ballpoint pens for different columns and white-out in case there were adjustments.

Later another doctor, a calm English woman, joined them and soon there were so many patients that brown folders of notes filled every corner of the large cottage and there was barely space in the staffroom to have a nice cup of tea.

They were young and modern, so they soon got a computer, and gradually all the green books and pencils and white-out and brown folders and self-carbonating pads and erasers were put in the shed out the back.

Some years later, the young man, who was now balding, proclaimed, ‘We need more space. We must join the boy doctors and build a modern health hub.’ And so they got together and built a type of ‘med mall’ where you could have a coffee and then browse the various services and decide whether today was for your teeth or your eyes or your shoulder or your blood pressure, or perhaps just a chance to buy a little tin of Vicks VapoRub.

In this modern health hub the desks were made properly by a man whose job it was to make desks and there was no sewing of curtains, just the endless writing of cheques. The people who used to write numbers in books now had a computer too, and their computer said, ‘Yes, the books will balance’, and they did.

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By then the young woman had shaved her legs and the young man wore the occasional collared shirt. They had built a house in the countryside and had two boys, who therefore had the misfortune of having two parents who were doctors.

The young woman loved being a doctor. She loved stitching wounds and scary emergencies and demanding patients and sad patients, and she developed a curious concern for those with mysterious ailments that could not be categorised, and she found that sometimes it wasn't obvious what ailed people or what helped them. She came to realise that the gubernaculum testis Hunteri was seldom the problem, and a prescription was often not the answer.

She had a curious nature, so she asked questions, and the more she asked, the more she learned.

And the more she asked, the longer it took.

And the longer it took, the more the patients waited.

And the more they waited, the harder the receptionists smiled.

And still she sat in her room, asking and listening.

And she came to understand that she was hearing stories.

And as time went by, she began to see she had her own story.

Postscript: The gubernaculum testis Hunteri is an obscure piece of foetal anatomy that guides the testicle into the developing scrotum. Such information one learns and quickly forgets.

The case of Dr J. J.

Some time after my father died of a rare lymphoma, his lovely haematologist presented him as a case at a grand round. My memory, from my time as a medical student, is that a grand round involved a lecture theatre full of doctors and professors, mostly men, in white coats. A couple of the white coats would present the case of a patient who had some interesting diagnostic or treatment challenges.

Case reports in medicine are a very stylised version of events, always starting with ‘Patient X was a X-year-old woman/man who presented with . . .’ My father’s case might have started with ‘Dr J. J. was a sixty-nine-year-old man with a five-year history of benign chronic lymphocytic leukaemia (CLL), who presented with discomfort and distention in his left upper quadrant’. I imagine the haematologist would have described his symptoms, the physical examination findings and the results of his laboratory tests, perhaps showing slides of his biopsies, his cells with an unusual pattern for lymphoma, and she might have solved this diagnostic riddle by referring to a search of the medical literature, describing similar cases of this lymphoma, a rare complication of CLL.

The thing that is poignant about this story is that for many years my father, as the postgraduate dean, had chaired these grand rounds. He would introduce the speakers and at the end of the case presentation take questions and comments from the audience. Invariably the white coats in the audience were probing, and incisively competitive, and the presenter was always slightly on the back foot, needing to hold their end up, so the grand round was quite a tricky event to chair.

To help you understand the dynamic, let me describe my father. He had a good word to say about, and to, everyone. But he was deaf. He had one dead ear from a surgical misadventure in his thirties, which he never complained about. The other ear had survived surgery but needed a hearing aid. He made up for this disability with oodles of charm passed down from his Irish ancestors, so he had an uncanny ability to sail through the white coats, smiling and joking, often not hearing what was being said.

His mother was widowed early, and he was the first person in his family to attend university, but he had a strong sense of purpose. His favourite line was, ‘Rules are made to be broken’, meaning that the merits of every rule needed to be assessed and a decision made about whether that rule was worth obeying. He loved ideas, believed we could make things better, make a difference. He relished being challenged by his kids, as though the younger generation were pushing him to think harder and more creatively. He had three feminist daughters and two sons who learned early how to change nappies, so he had his work cut out holding his own end up.

To his credit he spent a lot of time thinking about women in medicine and the challenges to the old order. He famously invited Sandra Coney to speak to a grand round. She was the feminist journalist who had exposed the abusive and unethical research that led to the 1988 Cartwright Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women’s Hospital. Sandra Coney wasn’t usually invited to speak to rooms of white coats but, as I have said, my father liked to break the rules.

Perhaps he is most remembered for his way with patients. He was the only specialist who would sit with the patient during the ward round. Never mind the trail of junior doctors and medical students standing around the bed, he would find a chair and sit, his eyes level with the patient's, giving them his full attention.

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And so, over those years that my father chaired the grand round it was convivial and energetic, and he always managed to steer the conversation to his own agenda, putting out his own challenges and wonderings. My enduring memory as a medical student is of watching him manage his deafness during question time. There was no such thing as a cordless roving microphone then, so it was pretty hard to hear the questions being asked. For the benefit of the audience my father would repeat the questions, or rather he would catch a few key words then turn it into a question that he thought was useful or interesting and then tell the contributor what an excellent question they had asked. He got away with it through sheer force of energy and enthusiasm.

A few years later, when the case of Dr J. J. was presented at the grand round, my mother was invited to attend and sat in the back row. It was very unusual for family members to ever be allowed to hear the discussion of a loved one's case. Occasionally patients might be wheeled in so the doctor could demonstrate a particular physical finding for the edification of the other white coats. But in my father's case, by the time he was presented he had died.

In telling this story, my mother described a rather dull, indecipherable presentation which ended with the haematologist putting up a photograph of my father. This was also unusual; case presentations did not involve identifying images of the patient being discussed.

But there he was, my father, larger than life, smiling down on the lecture theatre. It was now question time but for the first time ever, there were no questions. There was complete silence, my mother said: no raised hands, just an extended moment where the *case* in all its pruned medical austerity suddenly became a person, one they all knew and loved.

And after an awkward moment of hesitation, unexpectedly, they all clapped.

The inhabitants of the house with the turret window

I was brought up in a rowdy house in Invercargill with a turret window, warm kitchen and a coal shed out the back. The interior was full of older siblings who seemed to be perpetual teenagers, naughty teenagers, who wanted *peace*. My grandfather and his First World War cronies called them long-haired louts. The Marist brothers who taught them often sent them home to have their hair cut above the collar by my mother, who wore a pink kaftan and had a poster of Jimi Hendrix in the kitchen.

It was a home full of robust dinner table conversation, where the main topics were politics, sex and religion. Many years later I learned, by terrible faux pas, that in the best of circles politics, sex and religion should not be discussed at dinner, or at all.

We laughed with gusto. We showed affection by ‘taking the piss’ or what you might call ‘making fun of each other’, which I have also discovered is not a style found in polite society.

My mother taught me about words and the importance of being able to stand up and speak, whether it be a speech for a conference or a ditty for a birthday party. I can still feel her red pen hovering, about to correct my split infinitives, while telling me she loved it.

My brother Sean, the oldest, commandeered the storeroom beside the coal shed as his space. There he hosted gatherings of long-haired louts and girls who looked like Nana Mouskouri.

At 10, my sister Mary was taken to visit the priest because she had told the nuns she didn't believe in miracles. My mother was summoned, but I think perhaps the pink kaftan gave her away as the problem. My mother retold the story, both with and without shame, but in great humour as if to let us know that even high priests can be absurd.

Next was my older sister, Shonagh, who was my main playmate; dolls, knucklebones, last card, sewing. If we were hungry, we would cook pots of Edmonds custard or ransack the house for loose change to buy a packet of MallowPuffs at the dairy. If my mother knew we were going she might ask us to pick up a pack of Tiparillos, the thin cigars she favoured in an attempt to look elegant while smoking less. My father called them an oral contraceptive.

Trips to the dairy for Tiparillos were so regular that one day the shop girl asked, 'Again? Do you eat these things?'

Back then my mother would spend hours with Shonagh in the turret window, teaching her to read. She was severely dyslexic. My father lived by the maxim 'There is an opportunity in every threat', and Shonagh took this to heart, taking adversity in her stride.

The much younger one was Liam, full of giggles and bouncing curls. With three feminist sisters who all became working mothers, he was perhaps destined to become a stay-at-home dad, a role he took to with humour and purpose. And before Liam there was Dominic, who died when he was just five days old from a heart defect. We saw the small white coffin go into the ground and learned why adults sometimes cry.

I was the fourth child, and my siblings seemed to need my parents' help with life or reading or nappies, so I took to being self-sufficient. As one does in big families, I learned a lot about life from observing, and from being buffeted by the rowdy, good-natured chaos.

The holiday death toll

For as long as I can remember, the summer holiday period has been accompanied by the holiday road toll and, to a lesser extent, deaths by drowning or freak accident. You might wonder why these deaths are news at all; perhaps it serves as a coded warning to be careful, slow down, watch our step.

The holiday death toll is somewhat theoretical until one of the names released is your brother.

My brother Sean.

His life was a short sentence full of subclauses: he studied social anthropology, trapped possums and turned them into sausages, wrote the history of Otago rugby — a game he had never played — and married a Samoan woman, with whom he honeymooned in the rain up the Albert Burn as he researched the script for a documentary on the 45th parallel.

And then one day, aged 28, he was gone. Swept away down the Haast River, his body never found.

Recently I visited the bend in the river where Sean drowned. It is big country, granite peaks, dark bush and the sense of nature's life force, both beautiful and brutal. The rain was pouring down as it had been the day we searched for him, mist floating above trees, clouds of sandflies, the river, usually a charming trickle, now an ominous surge.

I had never visited the place in bad weather. We have always saved the pilgrimage for nice sunny days, not exactly having a picnic but at least feeling uplifted in the sense of being reminded, but with poignancy rather than devastation. But this time there was a grimness.

Standing in the rain I was taken back to another memory, of being the younger sibling, joining Sean on one of his solitary outings into the bush. I say solitary because we seldom spoke; we were both afflicted with our family's need to be in one's own head and we could handle companionable silence. He took me up a valley with no tracks, made mānuka tea in a billy over a fire, using water from the creek. We shared scroggin. I am weeping, now, remembering.

The sudden death of a young person is gut-wrenching, and Sean's death had a profound effect on my experience of living. If you have not had such a loss, you have been lucky. I was 21 and thought I knew a bit about life, but I had no idea you could feel an emotion so big, the size and weight like carrying a skyscraper on your shoulders. It was isolating, but I can still remember the small acts of kindness, the light touch of a hand on my back, those who were not frightened to see the enormity of it.

My visit in the rain was exactly 36 years after Sean had fallen while crossing the river. He was never seen again. Even after all that time I had a moment that day, which came out as a strange question to my partner: 'Do you think he did end up out to sea?' We had always imagined that the river had carried his body 47 kilometres down to the coast, and whenever I have visited South Westland I have imagined small atoms of him washing towards me in the surf, soothing me. But that day I had this terrible moment of thinking that perhaps all that time his body had been caught by an underwater branch then packed in with silt and maybe right now I was standing on his unmarked grave, not knowing. I felt sick.

It's the feeling that can come back, even now, decades later, out of the blue, a physicality, an embodied sensation of violent extraction as if suddenly losing part of oneself. The death of a child creates a big dark hole in a family. My mother says she lost a decade of her life grappling with filling it in.

If you have had a loss like this, I acknowledge the enormous load you carry. Our stories are all different, but I wonder what it is like to have a child die of a brain tumour, or a suicide in your family, or a parent drop dead in front of you.

This year over the summer I have noticed that, over and above the road toll, there have been almost daily reports of murder, and that gives me the same sick feeling. I wonder what it would be like to have my brother's life, or my child's life, taken by another and what sort of story I might be part of for that to happen, and I feel lucky. And I can't say why I feel lucky because I am weeping again. It will pass.

Caution. Patients.

I have a photo of my sister Mary, cut out of a newspaper. She is young, her gaze is a mix of innocence and ‘don’t mess with me’. She is standing in the driveway of a large psychiatric hospital. Behind her are huge rhododendrons and a sign. The sign reads, ‘Caution. Patients.’

I am 17. I am visiting my sister, who is in a locked psychiatric ward. For some reason the keys are enormous. The smell is disinfectant mixed with ashtray. There is a sense of menace, as if something could suddenly happen, but I am unsure where the threat is located. My sister is in a room with a peephole and a grey blanket. She is so drugged, she drools. She is 23.

Years later we are driving in a car together. Mary is now an internationally renowned advocate for psychiatric survivors and a mental health commissioner. I am a doctor, a somewhat suspicious occupation from her viewpoint but, more importantly, we are sisters. There is a moment where she says, ‘Peer support for people in mental distress is as good as anything doctors or psychiatry or therapy can do.’ And even though it jarred me, I knew there was a truth in it.

I am a teenager, in my family home. I wake to an anguished cry. It’s Mary. My mother goes to her. The lows have got so extreme that she cannot move or speak. After a few days she is back in elation, mania dancing her to the radio while the rest of us eat a sleepy breakfast. When the news comes on, she dances to that, too.

I have a video of Mary and her partner Sara and their three little kids, and Glen and Robert, the fathers of their boys. It is a TV documentary about queer families, and for some reason at the end they bring on a Catholic bishop to put in his 10 cents' worth. It's enraging. But Mary, in her forthright way, always with a chuckle, says something like, 'Well, I'm not sure a celibate man in his eighties who has never had a family has anything worthwhile to tell us about how to bring up kids.'

We are at the GP conference. I am watching my sister enter a panel discussion about mental distress. Her voice glides in, perfectly pitched to elicit some sort of humorous self-deprecation in the professional audience. As if it is obvious, she says something like, 'Of course, GPs can be specialists in earnest grandiosity.' I have to admit, I had a chuckle at my own grandiosity.

I'm holding a book called *Madness Made Me* by Mary O'Hagan. To my amazement a doctor beside me says, 'That book changed my life.'

Decades later, the sign is gone, but we are still grappling with the concept of 'patient' and what needs to replace 'caution'.

My mother is dying, and I am lucky

My mother is dying, and I am lucky.

She says she is lucky.

'I am at the end of a great life,' she smiles.

I am lucky she didn't die last year on that long night drive to hospital. None of us was ready.

I am lucky we can care for her at home. I'm lucky my family all get on, that we know how to laugh. And cry.

I am lucky to live in a country with a welfare state that pays for palliative care, commodes, catheters, medicines, carers and hospital beds.

I am lucky my mother is affluent enough to buy herself a wheelchair and a La-Z-Boy and lives in a home that is warm and roomy enough for grandkids on the floor.

I am lucky to be entitled enough to request more catheter bags or more care. That I can afford to take time off work to be with her.

I am lucky to work for people who understand whānau and what matters in the end.

My mother is dying, and I am lucky.

I am lucky to have a mother who has loved me, encouraged me, believed in me.

I am lucky to have had a mother who believed in herself.

I am lucky to have had a mother with the imagination to be tolerant, who welcomed everyone into her home. The worst offence one could commit in my mother's world was to be *tricky*. That's as bad as a person can get.

I am lucky to have a mother who can recite verbatim Milton's 'On His Blindness' in ED with oxygen saturation levels less than 60. I am lucky the doctor tending her knew the sonnet and joined her for the last line: 'They also serve who only stand and wait.'

I am lucky to have a mother who wants my partner and ex-partner at her table, together, who accepts her children's unconventional paths, with gusto.

I'm lucky we have had this year. We have had fun. We had a farewell family party nine months ago. We all did items, as we do. Her own message was, 'What matters most is caring for people, treating others well.'

The next day we planned her funeral.

'My death is a sort of adventure,' she says. 'Or maybe just an event. But you have to stage an event properly.'

My mother is dying, and I am lucky.

I am lucky to see my mother naked. I am lucky I can wipe her bottom for her, that she can laugh when she finally opens her bowels, and we all clap.

I am lucky my partner will drop her life to come. A sister-in-law who will give Mum a hug at 4 a.m., after cleaning up a mess. Sisters who never doubt the value of caring.

And Grandma's vision of loveliness: my niece, so soft and calm. Her Samoan mother, my drowned brother's wife, who arrives always with flowers, gentleness and four cooked chickens. And a busy sister-in-law who encourages my youngest brother to travel halfway around the world, multiple times.

I am lucky to have a mother who smiles every time a grandchild enters her room, who posts randomly on the teenagers' Facebook pages, who is still curious about their worlds. I am lucky to have a mother who at 86 is a role model for her 19-year-old gay grandson.

I am lucky to have a mother who has taught me the language of life. And love.

My mother is dying.

And I am lucky.

Much luckier than some.