

## Setting a small bird free

"I remember the day the diagnosis was finally made," says Nic. "I was standing in the hospital corridor. Mum had been admitted for a fall that broke her wrist. Suddenly the words 'motor neurone disease' made sense of this weird array of symptoms, but while my brain was going 'oh yeah, I get it' my heart was diving off a cliff, in freefall."

I'm sitting in Nic's kitchen. Over the top of the Magnolia tree, you can see the foothills of west Auckland snaking their way up into the ranges. Nic is my hairdresser. I've just started volunteering for a local hospice and we suggested to the hospice that her mother Rosie become my first client. My task is to visit her at home weekly for about three hours so Nic can have a break from her otherwise 24/7 task, to go and do simple things like shopping and banking, or just sleep.

Rosie's in the living room. Why do we call it a living room, I wonder, when so much more of life happens in the kitchen? It's more of a dying room, where Rosie spends her days rugged up on a la-Z-boy rocker, her diminishing frame engulfed by the chair. It's hard to imagine that a year previously she was a cuddly, feminine size. As we go in, the overweight cat wakes from napping on the steel-framed walker and disturbs an electronic speech writer that perches precariously on it.

Rosie drags the speech writer across onto her lap and starts tapping out words with one finger, burning with the need to communicate. Her uncoordinated movements make slow progress and she looks at it in exasperation, turning to Nic and waving her free arm to instruct her daughter to mind-read what she wants to say.

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Over the weeks that follow, Rosie's life story comes out in fragments. She's the eldest daughter of Ruby and George. Ruby was a psychic who earned money from reading tea leaves in cups. George made people more comfortable in the here and now by tooling the leather upholstery for train seats. Ruby's father had been a founder of the Masonic Order in New Zealand so the family had a philosophical and spiritual streak, which passed into Rosie as the desire to become an Anglican missionary nun.

"She was utterly crushed," Nic translated, "When the head of the order called my grandmother in following the interview and told both of them that Rosie loved beautiful things far too much to be accepted as a novice."

Whether perceptive, or just stating the plain obvious, the Rev mother was right. Rosie's bedroom even some 50 years later resembles the exotic world of a psychic, sparkling with jewels and gemstones, draped in rainbow scarves, bursting with colour, texture and trinkets.

Telling me stories demands so much physical effort on her part and mental concentration on mine that we take regular breaks. I read books to her, rub her feet with peppermint foot balm, feed her liquid foods and retrieve the tubes of lipstick that make a beeline for the sides of the armchair. We learn how to communicate soundlessly with one another, through our eyes and our spirits. The less she becomes physically the more transparent her heart is, shining with love.

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Rosie met her husband Michael while she was working at the Catholic shop in central Auckland. He was also psychic. They were married in 1960 and settled in Mt Roskill, a post-war state house

suburb. Like many of the men, Michael went to work on the Auckland waterfront. He was charming, handsome and somewhat charismatic, but also suffered from depression. Rosie discovered she had married a man who had frequent outbursts of anger, on-the-floor tantrums that required medication. He adamantly did not want children, hinting at some form of childhood abuse – the unwillingness to recreate his own experiences.

Nic arrived nonetheless, which exacerbated Rosie's fibroids and she endured a continual period until her doctor recommended a complete hysterectomy. In 1970 it was a radical operation.

"After 10 years", she tapped out on the speech writer, "all others operated died."

Sometime during the years of pain, Rosie had a moment of enlightenment. It profoundly shifted how she looked at life. She made the mistake of talking about that insight into other levels of existence at her local Anglican church and was promptly asked to leave. Enlightening experiences were not wanted there. Instead, Rosie found a book by Joel Goldsmith called *The Infinite Way* and started practising meditation. Based within a Christian framework, Goldsmith believed from personal experience and divine revelations that God was to be sought and found in "the secret, sacred silence of our inner kingdom". The shared human bond, he wrote, was to learn how to live harmoniously in the world yet not be subject to it. Rosie got hold of a bunch of tapes of his teachings and set up a meditation and study circle at her house, by then in the neighbouring suburb of Blockhouse Bay.

It was an era of suspicion about anything 'foreign'. An era of mobile salesmen, milk and bread deliveries to the door, the ice cream van and Indian greengrocers who sold fruit and vegetables from trucks. That's how Rosie met Harry, an agile sprite of a man who had been a disciple of Gandhi and who taught yoga. Rosie added yoga to her daily routine.

Michael shared the family inclination for community service, becoming an ambulance driver and a coastguard member. While saving others, he failed to overcome his own depression and died of a prescription medication overdose.

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Rosie is learning how to live in a body while not being subject to its failings. But the more control she loses over it, the more Rosie needs to control her caregivers. She's not above playing queen, gesturing imperiously with her hand towards something she wants me to fetch. There are days when we've just been through the physically challenging task of getting her to the toilet and back when she points with her hand to her bladder again. What do I do? Say no and risk an accident? She's got me over a barrel, so I place my feet on either side of her legs, bend my knees, wrap my arms around her back and lift. Safely in the commode, we navigate the narrow hallway and into the toilet. I pull her knickers down gently with one hand while holding her body in place with the other, then step out and part close the door to give her some privacy. Caring for a stranger in this intimate way, I have to learn that her dignity is paramount.

One day, just as she has emptied her bowels, the dog throws up in the hallway. I'm between two nauseating smells, feeling paralysed and wanting to cry. Why did I volunteer for this?

My heart gets tugged every which way. We'll be laughing riotously over a joke when I notice she can't wipe away the tears running down her cheeks. When I feed her, half of it dribbles back out again because she has such difficulty swallowing. I can't eat food in Rosie's presence because she gets distressed at not being able to eat. My needs clash with hers and selfish impulses rise up that

shame me. I have to remind myself she's not deliberately being difficult. Often I'm just a little bit late arriving, the product of trying to do too much with my life but also my ego's protest at being eroded in tiny, weekly sessions.

In-between looking after Rosie, I read up about Motor Neurone Disease. Clearly, it doesn't affect the sense of touch or hearing, nor a person's desire for affection. Above all, it doesn't affect Rosie's intelligence. What it does do is weaken the hundred billion or so neurons that roam around the brain and the spinal cord. These neurons normally send signals to the body's muscles to act. As they waste away, the impulse that turns thought into action is lost; limbs stop moving, it gets harder to speak or swallow, and even to breathe.

"Rosie gets sleep apnoea," Nic tells me. "She stops breathing sometimes. It's like a role reversal where I'm the mother completely sensitised to the slightest change. I wake up abruptly and have to go shake her gently back into breathing again."

Nic is being challenged by exhaustion. Sitting at the kitchen table with a cup of tea, we both agree that Rosie's biggest gift to us is to learn compassion.

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The garden she once lovingly tended has been abandoned. None of their friends from the spiritual church or community groups ever comes to visit now either, except Eric, who's in his 90s. They've known one another since Rosie was a teenager. Eric brings a small transistor radio that he parks on the armrest of his chair opposite her. Other than this background hum, they sit with one another in companionable silence. He demands almost nothing of her, or she in return of him. A deep peace exists between them.

Every six weeks or so there's a change in our routine, when Rosie goes into respite care at a private hospital. She hates the thought of being in an institution, even if it's only for a week. Visiting her there is hard for me too. I watch the afternoon drug trolley being wheeled into the day room and want to run from this claustrophobic vision of my own future. Where caregivers in rest homes used to make tea and help people get to the toilet now these largely immigrant workers are paid the minimum wage to give drugs under supervision and cope with increasingly complex sets of health needs. Some of the least skilled people are dealing with some of the most challenging. It's our values that fail people, not the individuals involved.

Each time Rosie comes home from respite care her condition has deteriorated a bit more. One time she has suspicious bruises. Although she falls often, and does easily bruise, these bruises are in places like her upper arms, places consistent with force. She uses her electronic writer to say that two workers tied her to her wheelchair and slapped her repeatedly in the face - all because she didn't want to go to bed when they wanted her to. Nic is furious, and nervous about sending Rosie for respite care. As a writer, I take up the task of producing a feature article about what happened, and why. The newspaper photographer takes her picture, looking hugely vulnerable and after the article is published a number of hospital residents approach her, pleading to talk to me about their situation. I just can't face it. I'm not brave enough. But, the hospital we 'out'd' undergoes a thorough change in culture and by the time I visit another client there it has become the hospital of choice.

Where Rosie most wants to go, though, is St Joseph's hospice. It's run by nuns. There's so much bureaucracy involved in these kinds of decisions. Just when the paperwork is about complete, Rosie

deteriorates rapidly. Barely more than bones, she spends her last twenty-four hours in St Josephs, coming full circle on her earliest spiritual longings to join the convent.

Rosie is cremated in a canvas sling, so the wooden casket can be recycled. Clothed in a dress she had made herself, her body is burned along with a pair of gardening gloves, letters and photos, and the Basil Brush that her husband Michael had given her because, he said, she was one foxy lady.