

The Other Jenny

Penelope Bingham

(Pseudonyms have been used)

'Wake up. Wake up!' The urgency in your voice penetrates my consciousness. Reluctantly, I emerge from a deep sleep. The clock on the bedside table tells me it is just after midnight.

'What's wrong?' I mumble.

'You have to get up. I've locked someone in the fridge.'

It is a cold night in the depths of winter and I have no desire to leave the comfort of my bed to investigate Fred's latest delusional scenario.

'There's no one in the fridge, I respond as I snuggle deeper into the doona.

'Yes, there is.' Your agitation is escalating.

Frustration surges through me as I breathe deeply and try to remain calm. I have learned the futility of trying to rationalise.

The glare from the lamp on the bedside table taunts me as I extricate myself from my warm cocoon. I help you as you struggle from the bed. The chill from the slate in the hallway causes me to flinch as I guide you through the doorway. With my free hand, I grope for the light switch as we navigate our way to the kitchen.

'See. There is no one in the fridge. Now let's go back to bed.' But I know sleep will now elude me.

Initially innocuous, the hallucinations, delusions and paranoia that are hallmarks of Lewy body dementia are becoming increasingly problematic. Every day there is a new imagined crisis to deal with. There are also regular nocturnal intrusions, with invasions by snakes, stalking tigers, kangaroos climbing the walls and deer running amok and creating havoc throughout the house. An uninterrupted night's sleep is a distant memory.

When I don't see what you see, you become belligerent but when I attempt to validate your confusion, I am accused of ridiculing you. This is not the Fred I know. This is the dementia that I am so ill-equipped to manage.

A quote I found defined an optimist as *someone who figures that taking a step backward after taking a step forward is not a disaster. It is a cha-cha.* I need to learn to cha-cha.

Another day, another calamity. Water in the roof was causing it to cave in, followed by the need to build an outlet to channel the water into the lake.

Then there was the day I left you asleep for twenty minutes while I made a quick dash to the supermarket. I returned home to find you distressed and berating me for going off and leaving you stranded in the ceiling for two hours with no way to get down.

Your vulnerability, your insecurity, your confusion tugged at my heart strings, as I struggled to reconcile the person you were becoming with the strong, fiercely independent man I had married almost fifty years earlier.

Intruders in your shed were a constant source of concern. 'What are they doing here?' 'I didn't give them permission to take over my shed.' 'That's my stuff in the shed. They have no right.' Followed by the accusation, 'You must be able to see them. I should be able to rely on you for moral support.'

By contrast, on one occasion, you inexplicably had empathy for these intruders. With gale force winds forecast overnight, I asked you to close the shed doors.

'No, I can't do that. The people in the shed won't like it.'

'I think they'll all have gone home if it's going to be a rough night.'

'No. They've dug a hole in the floor and are living underground.'

Remember to cha-cha.

As dementia entwined its tentacles more tightly around you, you became increasingly dependent on me. The most mundane tasks proved too complex for you to manage independently – showering, dressing, tying your shoe laces. Attending to your personal care in the mornings was stressful for us both. You felt frustrated, demeaned, resentful as dementia stole your independence and your dignity. At six feet tall and weighing eighty-five kilos, you towered over my fifty-kilogram frame. You were unable to process verbal instructions or assist in any way. A simple request, such as 'put your arm in the sleeve' was too complex and I struggled to physically manipulate you into your clothes. There were often tears and we were both exhausted at the end of this exercise and so often I silently questioned how long I could continue to care for you at home.

One morning, after yet another sleepless night, you resisted having a shower as there was a 'broken pipe' that needed to be repaired before the shower could be used. The house would be flooded. We would all drown. Why wouldn't I listen to you?

I was sleep-deprived, tired and short on patience. My assurances that I would call a plumber to deal with the problem as soon as you had a shower were futile. As your distress intensified, I conceded that I needed to retreat to avoid the situation becoming more volatile. Your words, as I walked away, exploded in my consciousness and will remain forever etched into my memory.

‘Why don’t you like me anymore? Why are you doing this to me? I just want to die.’
You were plummeting into a fathomless abyss where I was unable to reach you.

In the midst of our chaos a new demon raised its head – the two-Jenny phenomenon. You got out of bed one morning and asked, ‘Are you Jenny O’Brien?’

‘Yes Fred. I am.’

‘Well, I’m your husband.’

The first rays of morning sun seeped through the window and the tantalising aroma of fresh coffee permeated the room. Your eyes scanned the kitchen and the living area in search of signs of familiarity. ‘Whose house is this?’ you asked. When I assured you it was our house, you said, ‘I’m lost. I don’t know where I am and I don’t know who you are.’

It was mid-2014 and this was the first episode of Capgras syndrome. The first hint that a clone of me was emerging – an intruder who would invade our fragile world, uninvited and unannounced, on a regular basis.

Capgras syndrome is a psychological condition, causing the irrational belief that someone familiar has been replaced by an imposter. I was later to discover that twenty to twenty-five per cent of people with Lewy body dementia experience Capgras delusions and those with anxiety are ten times more susceptible. Fred was a prime candidate.

The other me materialised as we were driving one day. Dappled shadows formed intricate patterns along the tree-lined country road in the mid-afternoon. We travelled in comfortable contemplation, serenaded by a selection of songs from the sixties on the car radio. I was suddenly jolted out of my reverie when you became concerned about Jenny’s whereabouts.

‘Who do you think I am?’

‘I don’t know. We haven’t been formally introduced,’ was your cryptic response.

On another occasion, we were celebrating the mild winter sunshine by enjoying a rare afternoon in the garden – a pleasure we had shared throughout our marriage. With meticulous attention to detail, you had built retaining walls and terraces which were surrounded by the harmonious blend of native and exotic plants we had nurtured to create the setting for many family reunions and social gatherings. Our secluded retreat also provided a haven for goannas, blue-tongued lizards, possums and many species of birds. Cheeky magpies would tap at the kitchen window, reminding us that they expected to be fed and kangaroos came regularly to drink from the bird bath. Sadly, dementia had robbed you of the ability to engage

purposefully, but you still found pleasure in spending time with me as I struggled to maintain a semblance of order in the ever-encroaching chaos of weeds and overgrown plants.

As you pottered alongside me on this winter afternoon, you became agitated, saying you needed to find Jenny as you wanted her to find a botanist who could tell you how to treat the blue marks on the plant you were going to present to the prince. Ignoring the riddle of the plant and the prince, I repeated my default question, 'Who am I?'

'I don't know,' you responded, adding later, 'There are two of you and it's very confusing.'

During a shopping trip to Wodonga one day, I left you in a mall briefly while I stepped outside to post a letter. When I returned, you were riveted to the spot, adamant that you should wait for Jenny.

'Where is she? We can't go without her.' What had happened in your tangled neural network during the two minutes I had left you alone?

'Perhaps she has gone to meet us at the car. Why don't we go and look for her?'

'No. She said I should wait here.'

'Perhaps I could call her.' Unconvinced by my imaginary phone call, you tentatively followed me to the car where, I assured you, Jenny would be waiting.

When we arrived home almost an hour later, I entered the house ahead of you.

'Oh, there you are. I couldn't find you. How did you get home?' When I explained that we had been to Wodonga together and travelled home in the car together, you said, 'I wish you two would stop confusing me.'

There was one episode, however, when the appearance of the other me was welcome. It had been another night of fragmented sleep. I had been up to get you a drink at 3.00. You were awake again at 4.00 but my sleep-deprived brain drifted back into repose. When I woke at 7.00, you were on your knees leaning on the bed. I have no idea how long you had been there.

I tried to assist you onto the bed but my coaxing and cajoling merged into unintelligible turmoil in your confused brain. 'Perhaps I need to be in a home,' you commented during the ensuing struggle.

Again, the discrepancy in our sizes caused a problem but, at 7.00 on a Sunday morning, it was too early to call our daughter for help. When I eventually manoeuvred you onto the bed, you fell asleep immediately, exhausted by the morning's efforts. When you

woke later, your mouth was slack, your eyes distant and you were totally unaware of your surroundings. In the midst of your incoherent mumbling, you asked, 'Is that you?'

'Yes.'

'I'm not dead then.' The relief in your voice was palpable.

You succumbed to sleep again, commenting when you awoke, 'I've come back to life. I thought I'd karked it', adding later, 'I don't know who you are but you saved my bacon.'

For many years, it had been our evening ritual to enjoy a glass of wine accompanied by biscuits and cheese before dinner. We were reminiscing one evening about travel and holiday adventures, when the conversation turned to an idyllic year spent in Fiji. With a quizzical look, you asked, 'Have you been to Fiji too?'

'Yes', I replied and reminded you of the wonderful experiences we had shared there. Of cruising the Mamanuca and Yasawa islands, visiting villages and learning about local culture. Of the less than salubrious accommodation provided by the Ausaid project we were working for. The hotel, which boasted the grandiose name of 'The Waterfront Hotel', was, in reality, one step removed from Fawltly Towers. I recalled the privilege of often being invited to share a lovo at the homes of the locals. Of being initiated to a kava ceremony and expected to skull the bitter, muddy-tasting liquid in the traditional manner. To decline would cause offense. I spoke of attending a Hindu wedding and being guests of honour at a Diwali celebration as well as participating in Eid festivities with Muslim families. So many memories that formed part of the rich tapestry of our lives.

You were perplexed as to how I knew so much about you.

The other me appeared during another of our afternoon soirees. We had spent a delightful day with a friend and her lovely mum, who had Alzheimer's. It had been one of those perfectly clear days when you can see forever. The idyllic property was perched on a hill overlooking Buckland Gap, with spectacular views to Mount Buffalo in the distance. We enjoyed congenial company and a delicious lunch of quiche, made from eggs donated by the free-ranging chickens and accompanied by salad harvested from the lush vegetable garden.

When we arrived home, we settled on the front verandah basking in the late afternoon sun, the wine glistening in our chilled glasses. The air heavy with the intoxicating perfume of the prolific roses and surrounding lavender hedge. It should have been a congenial end to a pleasant day.

'Did you enjoy your day, Fred?'

'Not really.' My question unleashed a torrent of the problems associated with 'that other woman'.

'What's her name?' I asked.

'Jenny. She wants to get rid of me. She said she doesn't want me around.'

Remembering to cha-cha, I spoke of Jenny in the third person, extolling her virtues. 'I'm sure she didn't say that. She cares for you. She is there to help whenever you need it. She loves you and will always be there for you.'

Suddenly, we switched personas and the onslaught was aimed directly at me. 'You never talk to me. You are taking over everything. You won't tell me how much money is in the bank. You are trying to usurp my superannuation.'

The verbal assault gathered momentum. 'What are all these people doing here? Stop screwing me over. Tell me what's going on with all these people around. You say you have no friends, so who are all these people? Why are you doing this to me?'

This other woman, it appears, was often rude to you and you wondered when the 'grumpy one' would be on duty again. I'm sure there were many occasions when there was a hint of exasperation in my voice, particularly when I was tired or in the midst of yet another nocturnal disturbance. There were, however, also many instances when even my most innocent or well-intentioned comments were misinterpreted.

It was 3.00 a.m. and freezing cold. Minus three degrees, I estimated. You needed a change of night clothes.

'Come into the bathroom and we'll change your pyjamas.' This triggered a soliloquy about me being the Gestapo.

Remember to cha cha.

'Fred it's cold. Please come and change your pyjamas.' The soliloquy intensified.

'Please Fred. We need to go back to bed. Please come and change your pyjamas.' The monologue, like my frustration, escalated.

'You're a mean bastard,' you spat at me.

To my chagrin, at this point I lost my equanimity. 'I know. I'm a bitch. But if you can find someone else to deal with these issues at three o'clock in the morning, please feel free.'

This stopped you in your tracks long enough for me to change your clothes but my pleas for you to go back to bed were ignored.

'I'm speaking to you,' I said as you exited the bedroom.

'I'm not listening to you,' you threw back at me from the recesses of the hallway.

By 4.15, I conceded that sleep was futile and decided to get up. I found you in the study, confused and complaining about being cold. I ushered you back to bed and you fell asleep, while I retreated to the kitchen to console myself with coffee and tried to silence the persistent voice in the recesses of my mind that questioned how long I could continue to care for you at home.

Guilt and grief had become my constant companions and my journal was my confidante, the custodian of my innermost secrets. My fears. My frustrations. My loneliness. My sense of inadequacy in not being able to relieve you of the dementia curse.

For too long, I had been suspended in the void between caring for you and life without you. The shroud of the morning air, which hung damp and heavy, reflected my bleak mood when I found the courage to revisit the journal – the curator of my secrets. It revealed that you may have been right, Fred. There were two of me. I was turning into Jekyll and Hyde. Exhausted from the relentlessness of the caring role, too often I allowed my frustration to show. I hope you were able to forgive me over time. As I learned more about what was happening to your tortured brain; as this hideous disease permeated every aspect of your being; as I let go of my expectations of your capabilities and accepted your diminishing capacity as the new 'normal', I mellowed. You taught me patience, tolerance and unconditional love. You gave me a gift of grace.

Penelope Bingham is a retired teacher, literacy consultant and university lecturer, who was catapulted into the world of dementia when her husband was diagnosed with Lewy body dementia in 2013. With her caring role over, she is now writing her memoir of her seven-year journey navigating the dementia labyrinth.