

## CREATIVE WORK

Selected chapters from the memoir



# *Strange Country*

True stories from the borderlands of  
motherhood and child disability

by

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**In memory of my father  
Ernest Sydney Knight  
25.06.1921 – 01.05.1998**

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‘People tell you where they’ve been  
They tell you where to go  
But till you get there yourself  
You never really know.  
Where some have found their paradise  
Others just come to harm  
Oh Amelia, it was just a false alarm.’

‘Amelia’, from  
Joni Mitchell’s 1976 album, *Hejira*

## ***Introduction: the bird mosaics***

‘What, if not writing, will be the home of any self I can build from  
the bits I find lying around me as I look about after these years...’

Candia McWilliam<sup>1</sup>

I love mosaics, the way the shards of glass and chips of coloured tiles combine to make pictures that flash in the sun and leap out with brilliant light. Some years ago, I took a short course to find out how to make them. I learnt how to smash or cut glass and ceramic tiles into fragments with hammers and pincers, and then rebuild them carefully, piece by piece. I learnt how to glue the slivers down to keep them in place, and fill in the gaps with grout to make a new whole.

I dabbled in this for a while, but my interest waned. It wasn’t until I came across a new world of subjects for my work – birds -- that I was reinspired. I had visited an exhibition of paintings by artist Bill Hoffman in Christchurch; Hoffman’s career had stalled before he made a trip to Antarctica, where he observed the birdlife that had colonised one of the islands there. His work took a major turning then as he devoted himself to re-imagining and anthropomorphising those elegant creatures in paint.

My mosaics are based on birds that are closer to home: native species that visit my garden, such as a blue wren, a native pigeon, or a sulphur-crested cockatoo. There are some more exotic birds, too, among them. They come together out of random pieces and particles and meaningless fragments. Out of a shattering and a re-making. Their bright feathers shine and gold smalti eyes gleam, and their individual personalities somehow emerge in spite of my intentions. They perch on vitreous glass branches, or walk about, or appear to take flight with brilliant wings spread wide.

It takes a long time to make a mosaic, and each involves a thousand micro-decisions: finding the right mix of shapes and textures, of colours that complement and contrast, and then cutting the tiles to the right size. This making can be painful: the shards pierce my fingertips and drops of blood splatter across the work-space; the grout that fills the spaces gets under my fingernails and roughens my hands; the vinegarish fluid that I polish them with bites my skin with acid.

These birds, spirits of the sky, are created out of earthly matter: clay and minerals, or sand and soda and limestone, forged and fired until rock-hard and impermeable. Their parts are bonded firmly to their wooden bases. So it's a strange country they inhabit, these icons of the air. Trapped in their two dimensional worlds, my mosaic birds will never fly.

This textual mosaic, in contrast, is made with a writer's tools: words and sentences, paragraphs and chapters. It's a collection of anecdotes and episodes about my life with Amelia, the second of my three daughters, who was born with a severe disability. It's about our travels together through the strange country in which we have found ourselves. It's made from scraps of memories, and its shape has been pulled together in the hope that the pieces might form something resembling a story. The trouble is, it has a beginning but no end. It has little in the way of a plot, and the characters shift around precariously on the page. Its pieces are irregular and angular, sometimes sharp and abrasive. I try different ways of assembling them, but I can never get them to sit comfortably together.

There are ready-made templates available for the making of a story such as this: I've seen them in books and anthologies and articles and on the internet. They lay out the character archetypes and the plot variations and the optional underlying themes. But these patterns don't match the shapes or the colours I have around me: I can't, or won't, push my pieces into those prefabricated designs.

So unlike those birds, solid and immobile, this textual mosaic still seems to me provisional. I can't help worrying that at the very moment when the parts all coalesce and meaning emerges, it will falter and crumble. These fragments, in contrast to ceramic tesserae, are not cemented together with grout. Instead, they hang anxiously together, held only with a reader's generosity. And their lustre – if I have been able to polish them adequately – derives from a single source of radiance: my daughter, Amelia.

## ***Beginnings***

### **Midnight, 10 April 1990**

me hurtling on a gurney, push-push-pushing me they are, wheels squealing, through deep passages, through tunnels hung with plastic grey, through clanging doors, through draughts like cold swords, through dark and damp wan light, through the midnight spaces;

my face hot, body hollowed, oozing blood water sweat colostrum, flesh sticky, breasts straining, belly loose and wobbling, thick with emptiness;

you there, swaddled and sleeping in your new womb of blankets, in your plastic cot, trundling along beside me;

my body aching with hunger, my mind bright with triumph, push-push-pushing still, until they erupt us into that shrieking light

of the maternity ward; don't want to be here in this noisy bright, but they glide us past fluorescent nurses and park us in a darkened room where we disturb the huddled shapes of new mothers keen for sleep;

had planned on the mother-and-baby unit, but no room in that inn tonight, so we take up our tidy corner place here, you so far away now in your cot still sleeping,

and me with my mind alight my pulse too loud my heart too creaking full for sleep must pass this thundering night with its gallery of glittering memory-scenes alone.

### **Afternoon**

4.00pm: early warning: a tightening, low low down, a pain like pleasure; then a clutch and grasp, gasp, beneath descending baby head. I laugh, grab hand of firstborn daughter: 'baby's coming,' I say;

phone husband's work, no answer ('pick up!' I hiss-whisper); then someone speaks: 'baby's coming,' I say, 'please find him now; tell him to come.'

## **Morning**

10.15am: doctor's rooms: waiting women line the walls; they stroke their rounding loads, they watch the clock and sigh; weighted with waiting, they are, filled with the drama of body, and the narrative arc that holds each in its thrall;

I'm past it now, overdue a week, my story running over time, my body straining at its boundaries;

sick with fear I am, stifling the panic in my throat, blinking back the tears that well in my eyes; a single thought plays over, shouting louder at me as I wait: 'there's something wrong, there's something wrong with my baby';

the other women wait on, and turn their pages;

then the doctor calls me, and I heft my weight onto my feet, and when the door closes, I shudder and release the fears, and they fall like wet splinters on the carpet; he does the tests he checks my undercarriage;

'everything's fine,' he says, 'it's only nerves', and then, 'tonight's the night';

I let my fear go and carry on.

## **Evening**

5.00pm: faster and stronger: firstborn rides with me, kneels on the floor with me, back on her haunches with me, rocking, counting, breathing through spasms that clench and squeeze, that fade away to peace then return to wrench us harder still;

evening falling, rain falling, husband rushes in, face awash with running and expectation (it's always raining when my babies berth). He phones my mother he rubs my back he feeds my daughter he gathers my bag that is zipped up and bulky by the door like a tight-lipped housemaid;

then out of the drenching dark my mother appears, presses wet lips against us, we hug daughter good-bye and launch ourselves into the trembling night; 'tomorrow you will see the new baby,' we promise, and the vice strikes me once more over the threshold.



7.15pm: hunched on the back seat I am, pillow bunched under quivering shivering quaking bulk of belly, panting hard, biting on polyfoam, rain beating sheets and windows streaming with watery bright city light;

nowhere to park, we circle rabbit warren streets, find a spot (though will be booked and fined); I struggle out of car cocoon, hatch onto the flooding road, it must be a thousand miles to the hospital doors.

## Night

8.00pm: why must they take so long? forms signatures papers, like lures; I keel over, a thrashing mackerel on the floor hooked again by pain sharper than an angler's knife; they hoist me up and land me in a chair, wheel me into a lift down a corridor into the birth centre; it's dark and calm and quiet but my body screams and fills the empty space with loud insistence;

hands and voice of midwife gentle, she strokes and pokes, checks dilatation, times contractions, takes blood pressure, listens to heartbeat, writes things on paper, 'it will be a while yet,' she says;

I am strong and fierce with purpose now, a bloated valkyrie now, as the searing pain comes harder and longer, less time between them now; keeping strong and centred now, breathing through every assault;

husband rubbing my back, rub-rub-rubbing so hard that his hands ache and tomorrow my skin will be chafed and bruised; husband breathing with me, so focused on me that he almost feels my pain;

10.00pm: the final ripping tearing stripping back, and my body hits the limits, the great force of you right there now at the very brink;

'quick, get the midwife,' I cry, 'I have to push',

and then the waters break as I pant back *push one*; midwife arrives, fussing with instruments and oxygen and sheets and other things;

then the avalanche descends once more, *push two*; pant hard, hold back, I'm on all fours, they see head crowning from behind, too late to shift position;

and then again, *push three*: I feel your head break through, my flesh taut and tight with tension, and then your slippery breadth of shoulders; midwife catches you, and I turn around to see:

squalling baby girl, face scrunched tight, body unfolding and pinking up, eyes squinting against light, arms thrown wide, purple cord still binding you to me;

I smell your vernix-ed head; I touch you, run moist fingers along the length of you; I take you onto the now soft cushion of my belly and wet you with my tears;

but midwife tells me there's more work to do, and one more great heaving push lands placenta between my legs;

then your father cuts the cord, and you are free; he takes you up and fits you snug into his huge hands, and gives you back to me;

I put you to my breast to quell your sobs; you quieten; then midwife takes you, does her checks and measures; she passes you back and smiles because, she says,

you

are

perfect.

## ***A name***

*Amelia*. Made of sighing vowels, bilabials and liquids, it's a name like a kiss.

Its meaning, though, is less romantic: a variant of the medieval name Amalia, from an old Germanic word, *amal*, it means 'work'. Amelias, it appears, are industrious souls.

The diminutive form is Millie: a name to become you, and for you to become.

Long ago when I was a girl, I entered competitions in the women's magazines my mother brought home. 'Name this special edition doll and win a prize', one urged. The sweet porcelain doll in the picture was all flounces and eyelashes and ringlets. I thought long and hard, then it came to me, the perfect name: *Amelia*. It was a name that was seldom heard back then. I sent in the entry, I didn't win the prize, but the name stayed with me, waiting for you.

There have been other, real Amelias, notable ones, who were not so meekly sweet. Like the most famous one who flew, too high and too far, and became a symbol for striving women but also a warning for those women who dreamt too hard and let their dreams come true.

I dreamt of, or maybe for, you when you were six weeks old. I sat in a dark auditorium next to your father; the stage was shining bright and the tinkling laughter of the stars up there rang out like bells across the black space. Then someone called your name: *Amelia*. I glimpsed the shape of you in the wings, and then you came light as air across the stage in a gown that sparkled, with your hair so very white around your shoulders. They handed you your prize, a silver trophy, and you smiled into the emptiness, and the applause fell like gentle rain around you, and there you were in the midst of it with your midnight eyes all moist, and I felt the great swell of pride within me, I felt my blood grow sweet with it and my heart beat fast with the rhythm of it and then I woke.

But there were other dreams, too. Two weeks before you were born, before you were named, I dreamt that I was falling. Caught in mid-air I was, my belly huge with you, and we were falling from a great height. Above us was the cliff-top, a craggy solid rock, and standing there, leaning far over and reaching way out to us were your father and your sister. I could see your father's mouth contorting, I knew he was shouting down to us, but his words were lost to the wind. I lifted my arms, I tried to ride the currents back up to them, but it was too late. We kept falling, and I knew then that there was no going back.

## ***Hospital***

The woman wheels the pram with her baby down the corridor under sharp fluorescent lights. The linoleum floor reflects the blurred shapes of those scurrying in front of her. She checks her papers and follows the arrows, then she parks the pram at a nurses' station. She waits until one of the nurses, professionally indifferent, takes the papers and leads her into a room with eight beds occupied by seven children and an assortment of adults. The nurse indicates that the empty bed is for the woman's baby.

The woman smiles politely at the people around her and slips her bags off the pram handles. She lifts the baby out of the pram and holds her close to her chest. Then she lays her down on the bed that is much too big: the small parcel of her child is lost in the expanse of cold white sheets and cotton blankets. Around them the room throbs with noise, a television blaring, children shouting. An older man with a 'Volunteer' badge sits beside one bed, reading to a boy who has a bandaged head. Parents coax and cajole and joke with their children. The woman speaks to one or two of them, and learns that their children have been here for days, sometimes weeks. She feels a rush of sympathy, and is relieved that she and her baby will be here for just one night.

Her baby begins to cry. The woman picks her up and cradles her, singing softly into the baby's ear, as she always does. She drags a chair over to the side of the bed, and facing toward the wall she unbuttons her blouse and begins to breastfeed. The baby settles into a gentle rhythm of suckling.

Three weeks before, the woman and her husband had taken their baby to see a neurosurgeon at this hospital. For some time the woman had been worried about her baby, and she had endured a round of appointments with GPs and paediatricians. No one was particularly concerned: the baby was thriving, her birth weight was good, pregnancy and delivery normal. The woman was over-anxious, they said. But the baby had an umbilical hernia – a pouch of intestinal flesh would push through the socket of her belly button after a feed or when she coughed or moved her bowels. This was not a worry, the doctors said; most of these hernias heal themselves by the time a

baby is a year old. But the baby's head was an odd shape too, and was not growing at the appropriate rate. A paediatrician referred them to the neurosurgeon.

The strain was telling on the woman: her face was pale and anxious, and she was losing weight. Her husband was optimistic: there was nothing wrong with their precious second child, he said. The neurosurgeon, a man in his sixties, looked over their baby, and shone a light into the pupils of her eyes to assess if there was any pressure on her brain that might interfere with healthy brain growth. He wrote a page of notes before turning to them. He explained that their baby most likely had craniostenosis, a condition in which the plates of the cranium fuse too early. These plates are soft and flexible at birth to enable the baby's head to travel down the birth canal, he said. During the period of rapid brain growth following birth, the cranial plates remain flexible in order to expand with the brain that they are protecting. In rare cases, the plates may fuse early; without surgery, the brain as it grows experiences pressure, and this may lead to brain damage. The parents listened wide-eyed as the surgeon spoke. The woman's heart was beating frantically at the prospect of her tiny baby undergoing brain surgery.

'It's quite a routine operation,' the surgeon said. 'I wouldn't worry too much about it.' He said his diagnosis would need to be confirmed by CT examination. He said the procedure would be scheduled as soon as possible, and for first thing in the morning, to assist with their baby's feeding schedule. The baby would need a general anaesthetic so that she remained still throughout. She would need to stay in a hospital ward overnight.

Then the woman asked, 'Could it be anything else? I mean, if it wasn't this craniostenosis?'

'I wouldn't think so,' the surgeon answered. 'She's bright, she's alert, she'll be fine.'

On the way out, her husband squeezed her hand. 'We'll get through this,' he said.

The baby has stopped suckling and is asleep now in the woman's arms.

A clash of tin lids on a trolley outside the room startles her baby awake. It's 5pm, and they are bringing through the dinner trays. An orderly slides a tray onto their

table. The woman lifts the lid, and finds something unidentifiable on the plate beneath. She takes her baby out into the corridor and wanders around until she finds the children's play area, where she props the baby up on the floor. Time moves very slowly. She takes her baby back to her bed, feeds her from the jars of baby food she has brought and changes her nappy. The woman is hungry. She wants to get some food for herself and she wants to use the bathroom. But there doesn't appear to be anyone around who will look after her baby while she is gone. The nurses are all so busy. After some time she asks at the nurses' station if a nurse can keep an eye on her baby while she pops out for a moment. She dashes away, and buys a sandwich and a cup of tea from vending machines.

Much later that night she finally settles her baby to sleep. She takes her bag to the parents' room with its line of thin beds, and gets a few hours of fitful sleep. She hears her baby's cry, a sound only she could recognise, several times, and she gets up to tend to her. She is permitted to breastfeed her baby at 4.00am for the last time before the general anaesthetic, but her baby is too sleepy to feed well. At 6.30am she is called to take her baby down to X-ray. They wait, and after two hours she intercepts a nurse who is bustling past, to ask why there is such a delay.

'An MVA,' the nurse answers. 'X-ray priority.'

'MVA?' she asks.

'Motor vehicle accident,' the nurse replies and scurries away.

The horrors of a hospital, the woman thinks gloomily. She finds a phone and rings her husband to tell him about the delay. He promises to be there around lunchtime. Soon her baby begins to seek her breast, and then to wail with hunger. They walk up and down the corridor, up and down. Her baby's face is puckered with distress, and she battles her instinct to give in and feed her. At 11am they are finally called in. She croons to her squalling baby, who quietens then descends into anaesthetic peace. The woman is told to leave and wait for her child in Recovery. She realises that she hasn't eaten since the sandwich last night, so she takes the opportunity to find some food and drink.

In the cafeteria she reflects on her journey over the past few months. She remembers the day when her husband and elder daughter, almost three, came to pick her and their

new baby up from the women's hospital to take them home. They stopped at a bakery in Glebe to buy cakes. When her husband returned to the car with the packages, she kissed him and said, 'I know this sounds corny, but I feel like my cup is running over.' The elements of their lives had come together to create a new, astonishing reality: the small Federation house they had transformed from a hovel into a beautiful home; their amazing, exuberant first daughter; her university teaching job; his successful public service career; and now the gift of this new, perfect baby. The past had not been so easy: they had faced a major family schism several years before that had delivered a long stretch of anguish and pain and sadness. This was now their reward.

But the last few months had taken her into different territory. Bit by bit the certainties that they had built together were challenged by this new fear that there was something wrong with their baby. Most of the time she felt very alone with this fear. She was hoping that today a diagnosis would be made. If an operation was needed, they would get through it, and they would do all they could to make sure their little daughter recovered.

She follows the rambling corridors through to Recovery, and waits until she is called. Her baby is in the uncomfortable throes of waking from a deep deep sleep. After twenty minutes or so they shift the baby onto a trolley and wheel her back down to the ward, the woman trailing behind. Not long after, the woman's husband arrives. She is relieved to see him, to feel his positive energy around them. They must wait now to speak with the surgeon when he makes his rounds.

They find a parents' common room where they chat with other parents while their baby sleeps off the anaesthetic. It's a long wait and they joke about the status of these surgeons who have all the power and call all the shots. The woman checks on her baby, and the mother of the child in the bed opposite says to her, 'Your baby is so beautiful. I've never ever seen such a gorgeous child.' The woman flushes with pride. 'Thanks,' she says. It's not the first time this has happened: she is often stopped in the street by complete strangers who comment on her baby's ethereal beauty.



After another half-hour, a nurse tells them that the surgeon has arrived. They hear his stentorian voice booming out their daughter's name, and they take their places at the side of her bed.

'Sit down,' he commands. 'You'd better sit down.' One of his registrars hurriedly draws the curtains around their baby's bed. Another scurries to assemble chairs. The surgeon is shouting; he speaks at rather than to them. The woman and her husband remain standing.

'Unfortunately,' the surgeon says blankly, 'I've got bad news for you.' A pause. 'In fact,' he says, 'it's devastating news.'

The woman and her husband look at each other. The woman feels a deep hollowing in her stomach.

'What do you mean?' her husband demands.

'The problem is not what I originally thought,' the surgeon says. 'It's not craniostenosis.'

A long pause.

'What is it then?' her husband asks.

'It's ... it's quite catastrophic,' the surgeon says.

The woman sinks into the chair, is engulfed by a cloud of darkness, can hardly breathe. The face of the surgeon swims before her.

'What do you mean?' her husband says, an edge of anger in his unsteady voice.

'Well,' the surgeon says, 'the brain is not developing normally. There are large spaces in this baby's brain. It's ... it's full of gaps.' Another pause. 'There's nothing *I* can do. Surgery won't help. You will need to see a neurologist.'

'When?'

'*I* can't tell you that,' the surgeon replies. 'You'll have to make an appointment.'

The woman and her husband look at each other across an intolerable distance.

The two registrars have been gawping on the sidelines, but one now sees the need to take action. 'I'll get an appointment for you,' he says, and strides out to the nurses' station.

The woman rallies a little and voices, or rather breathes, her worst fear. 'Will she be retarded?' She looks over at the baby on the bed.

'I don't know,' the surgeon says. 'Let's put it this way: she won't be a rocket scientist.' Another pause. 'You should come and look at the films,' the surgeon says. 'Then you can see the brain malformation for yourselves.'

The surgeon opens the curtain and the husband follows. The surgeon looks at the woman. 'You, too,' he says.

The woman shakes her head. She has had enough information for one day. She doesn't want to see inside her baby's brain. She wants to stay where she is, with her beautiful baby.

'I'll come,' her husband says to the surgeon. 'My wife will stay here.'

The mother of the child in the bed opposite sees the woman through a gap in the curtain. 'Are you all right?' she asks. The woman cannot answer. She feels a vast emptiness, as if a large part of her, her soul maybe, has just disintegrated. She stares at the baby on the bed, the very beautiful baby that is, was, hers. She waits; she doesn't know for how long.

The registrar returns and chatters about appointment times and places. She doesn't understand what he is saying, nothing makes any sense. She can tell that he is trying to be kind. He explains again about an appointment with the neurologist. He says that the first appointment he could get is in six weeks.

'Six weeks?' she repeats. The baby begins to cry. She picks her up, and wants to shield her from these people, this hospital, this knowledge. But the baby senses her distress, and cries loudly. The woman puts the baby back down on the bed.

Her husband comes in. His face is colourless. He tells her about the films: there are empty spaces around the ventricles of the brain; the surgeon doesn't know why. He begins to tremble: the surgeon told him that most of these children don't last for long; they get sick, they are prone to pneumonia or some other disease. As if that was for the best, nature taking its course.

She tells him about the appointment with the neurologist, that it is six weeks away. He tells the registrar that can't be possible, they must see someone now to explain all this. The registrar shrugs: there is nothing he can do; he offers to organise a social

worker to see them. But they don't want to see a social worker. They want to get out of this place. They ask a nurse if they can go, and take their baby home now.

The woman packs the baby into the pram. They walk to the car park and place the baby into the capsule in the station wagon. They drive through the early evening traffic, across the city, to their home. They don't speak much; their words seem disconnected and unreal, as if they are coming from some other, distant place.



## ***Not a Picasso woman***

Night is falling all around me, and I see nothing but the four Picasso women in my mind's eye. They hang on a wall in the long white hall between the foyer and my room, and they are haunting me. They all have the same name, *Nude in armchair*<sup>2</sup>, but they are different, and they keep telling me things I don't need to know.

I try to blink them away but they cling stubbornly.

The first of them is serene and blue and sexy, all lush curves and round breasts, plump cleft between her thighs; beautiful, and full of her own post-coital smugness.

The second is in agony or orgasm; her face is a hideous mask; her limbs flail like tentacles; her sagging breasts loll; her vulva points to a womb that is marked like a bull's eye. In the top left-hand corner is a pane, like a viewing window. She is there to be watched in the throes of her horror. She is exposed, grotesque.

The third, in blues and greys, is monumental. Her body parts are displaced, but immobile as stone. Her face is a closed envelope, her eyes are holes. Only two pieces of her – her right hand and her lower abdomen – rise whitely to the foreground.

And the fourth has left home. Distilled into sculpted spheres and curving masses, she has receded, and there is no vestige of humanity left in her. She frightens me: she is the last phase in some inevitable process of disintegration.



But I am not a Picasso woman. My scattered parts are not contained by a frame, nor frozen into a single moment. I am not pressed flat into two dimensions, to be hung and devoured by hungry spectators in some public hallway. Instead, my pieces drift in free fall; they float out into the evening gloom; they merge with dark shapes and shadows; they wander through time and space, and threaten to abandon the skin that contains them.

Then someone speaks; it could be to me. I quickly reassemble. Under a jagged scrap of city night sky I am, in a courtyard lit by wan night lamps, with a ragged pack of people on cold plastic benches with hot drinks, and cigarettes that send thin rivers of smoke into the black air. I don't want to be with these people I don't know. They will ask me who I am, and I have no answer for them.

'So why are you here?' A variation on the theme. It's a man, late forties, fifteen or more years older than me. He is big, and good looking in a rough-and-lived-in kind of way. He sits beside me and drags hard, and blows his smoke across my face and into the shadows. I hesitate. I don't want to answer him, I don't want to confess, but then I do.

'Ah,' he says, 'I didn't think you looked like the rest of us.'

It's my first night here, and I don't yet know who the rest of us are.

'Rough, eh?' he says.

I tell him I will be here for only five days. That seems to contain me, to make things finite. He turns away. He wants to share his story, but mine is too different. Instead, I huddle inside my skin and listen to the others. Their stories come in snatches and snippets that I try to piece together. Their stories are new to me, and they free me for a moment from my own.

Then, from inside the building comes the sound of a bell or buzzer. 'What's that?' I ask.

The late-forties man answers. 'Meds,' he says, and the others butt out their smokes, and I follow them inside and onto a line where pills are handed out to cushion against the long night ahead.

I am here because I am not coping; that's what they say. But it's worse than that: I am here, I think, because I am disappearing. It's as much as I can do to identify the

various pieces of my scattered self; I'm not sure for how much longer I will be able to tack them back together. Coping seems to require the act of a will I no longer possess.

I'm here because I spoke when I should have kept silent. I said things that no woman daughter sister wife mother should say. I sat in my pretty kitchen, in my pretty house, with words taking ugly shapes around me.

When I arrived this morning, my husband stayed to have morning tea with me. One of the nurses asked us why I was here. 'These things happen,' she said.

My husband tried to explain how it was affecting me. 'She's a perfectionist,' he said.

'Well, then,' the nurse said, looking straight at, or through, me, 'you'll have to lower your standards then.'

I did not understand what she meant. I tried to hold on to my husband, but it was time for him to go. I could tell he wanted to go.

On the second day I am taken up by the routine of the place. I follow instructions. I sit on a lounge chair in a large room while someone in charge asks questions and others who know the language speak across the spaces. I visit the craft room and I toy with scissors and scraps of fabric but I do not make anything of use. At the cafeteria I fill my plate and eat more than I have in months. I share a room with a woman I can't remember.

After dinner my family comes to visit me: my husband, my daughters, my mother. Shame floods back over me when they arrive, shame that I have retreated from them. I sense their disappointment. I hold my baby who is now just over a year old; I show her to my room-mate and the nurses; they say how beautiful she is; they look at me quizzically, as if they can't understand what my problem is. I put my arms around my four-year-old, and tell her that mummy will be home in a few days. I put my arms around my husband. 'I'm sorry,' I whisper.

I learn who the others are. This floor and the one below are mainly for addictions, for people caught up in the endless cycles of substance abuse. Their stories are about how long they were clean and how they busted, and how much they want or need a drink. Upstairs is for eating disorders. I see young girls dart down the stairs, pale and thin as rakes. Each life is moored in its own pain and fear and uncertainty.

There is no-one like me here, though. It makes me wonder where the grieving mothers go. Or if they are all able to cope. Unlike me.

Later that evening it is time for the scheduled relaxation session. The others and I bring pillows from our rooms and lie flat on the floor in a large room. The lights are turned very low. While gentle music plays a nurse takes us through the script: we are on the beach with the sun warming us; our bodies are becoming heavy; our minds are emptying of thoughts and worries. But my mind does not empty. Into the stillness and the dark come ripples, then waves, then great walls of thick viscous thoughts that break over me, and I am caught again in the vortex that pulls me down, way down. At the bottom of the vortex the thoughts surge and spiral, they toss and thrust, they assault me with their accusations, and their poison floods through me like cold fire. My breathing comes fast and shallow. I grab my pillow and run away, back to my room.

A nurse comes after me. She is kind, and says soothingly: 'You were having a panic attack. It happens. Perhaps you are not ready for relaxation group yet.'

The next morning I am scheduled to see a psychiatrist. I must pass by the Picasso women on my way to the waiting room, but I do not look at them. I sit patiently, and look at magazines, and wonder what I might have to say. I think back to another waiting room: the obstetrician's rooms in Macquarie Street, where I sat through two pregnancies, waiting for two babies. On the wall in that room there was a line drawing, an abstract, of a pregnant woman with ballooning belly and floating breasts, but, unlike the Picassos, she was whimsical and funny. I remember my own body then, how substantial, how replete it was. How incontestable. But then I recall my final visit there, waiting still, my baby a week overdue, tears held at bay as fears flooded my mind, that something was wrong, that something was wrong with my baby.

'I think there's something wrong,' I had breathed, when the doctor ushered me in.

'It's just nerves,' he said, and he did the checks and tests. 'Not a thing to worry about,' he said. 'Everything is just fine. You'll have your baby tonight.'

And I did, and she was fine and beautiful and mine.

But he had not known.



Then a young Asian woman with a file calls me in. She's the registrar. She looks through the file and asks me about what happened just before I came here, about the psychiatrist I had been seeing, the one who filled in the paperwork to get me in here.

I don't tell this to the young woman, but I don't think the problems with that psychiatrist were my fault. I could be wrong. I was referred to her by our GP, who had said to us, 'You have to fight this thing. You have to do whatever it takes. I think you two will be able to get through this on your own'. We tried; at night we held each other tightly on our bed that was a boat under a mosquito net that was a sail, and rode the stormy sea. But I was being pulled away, into the vortex. I went back to see the GP, to tell him I needed help. He looked through his referral list and found a woman, a psychiatrist, not far away, who was young, whom he thought would be good for me. I went to her. I imagined that she would follow some therapy guidelines, that she would know the right things to say to me. But she didn't. Each time I saw her, I felt worse. I told her about the vortex, but she didn't seem to understand. One day she said loudly, clearly frustrated with me: 'But of course it's not your fault. If it was your fault, then we'd have to deal with that.' After I hadn't seen her for several weeks, I noticed that she seemed to be pregnant. I asked her if she was, and why she hadn't mentioned it. 'It's just not your business,' she said. I didn't go back.

I tell the registrar some of this.

She is joined by a middle-aged man. He looks smart and well-groomed, with a neatly trimmed beard. She tells him about me, and then she leaves the room, and I am alone with the man who is the consultant psychiatrist. He asks me some more questions about my baby, about her diagnosis, what it means, and how I feel. He hears me talk about the shock and bewilderment. He hears me say that I am trapped in a whirling fog of guilt and blame, that I don't know how to get out of it or if I should be able to. He hears me say I am worthless. He is patient; he listens and nods. He doesn't say that 'bad things happen to good people', or 'you have been chosen by God'. He doesn't tell me to snap out of it, or that it has been six months and I should have accepted it by now. He doesn't say that I should be concentrating on my daughter and her needs; that I am selfish to think about myself.

After a while he looks at me carefully, as if he is studying me. Then he says, 'This is all about your woman-ness.'

Something stops inside me. Something stills me. I don't understand it, how this well-groomed, well-off, middle-aged man can offer me this simple truth. How he knows. No-one else has got even close. I nod, and tears stream down my face.

I want to say, but all this has negated me as a woman; this makes all my efforts, my accomplishments, my very body, come to nothing. But I am silent.

Then he says: 'Your woman-ness has not been diminished by this.'

How not? I want to ask, but don't.

'What has happened to you is part of your woman-ness,' he says. 'Right now, you don't think so, but you will be able to get through this.' Then he says some things about nature, and motherhood, and the nurturing impulse.

I am not sure how to respond, but I nod, still afloat on the buoyancy of his words.

'I am in such foreign territory,' I say. I tell him that I don't understand it.

Before this, I had only ever known two people with disability.

One is my husband's cousin. She has an intellectual disability and a hearing impairment, the result of an illness in infancy. Even before this happened to us, we saw that that family was defined by the young woman's disability, that they defined themselves by it.

The other goes way back. One of my best friends in primary school had a younger brother with intellectual disability. In those days he was 'retarded'. My friend and I used to play recorder and collect money for the Red Cross. Her mother made toffees and butterfly cakes for her birthday parties. Her younger brother could not speak; he used to point at things, and my friend would fetch them for him. 'They just baby him too much,' my mother said. 'They should make him do things for himself.' My mother did not speak much to my friend's mother; it was understood that their family inhabited a different world.

I don't tell the doctor any of this.

But I do say that I can't fathom why I have been plunged into this nether-world, a world that skulks somewhere beneath the real one. I wonder how I could have been unaware of it in the past, when now it seems to be all around me.

I tell him I can't make sense of it, why it happened to me and my baby when there appeared to be no risk, no danger.

My husband's mother had eleven babies, each born healthy, despite a host of pregnancy problems. My own grandmother was one of seventeen; one of her sisters was born with half a little finger on one hand, but apart from that, all normal.

I don't tell him this.

He listens to my silence, and nods his head. Then he tells me the time is up, and I will see him again tomorrow.

The next day I tell him about the vortex, how a single thought can sabotage me, drag me spinning to the bottom, throw me into a centrifuge that turns me to residue. That my mind constantly probes and plumbs the depths, searching for something else to feed the hungry beast of self-blame. He asks me to tell him more. The thoughts are all about things that happened in my pregnancy, I say, or they could be from long ago, about things that I did when I was younger, mistakes I made.

'What sort of things?' he asks.

I hesitate, because these are my secrets. Then I tell him: the thoughts are about having a bout of asthma at the time of conception, about exercising too much, about reports of lead in the Sydney soil, about painting a bedroom, about eating shellfish, about driving too far in late pregnancy, about drinking cloudy water from a North Coast water supply, about maybe having viruses I didn't know about, about a child falling over when I was babysitting when I was fifteen. There are more, but I can see that his eyes have glazed over.

He says: 'We will organise for you to continue to come in as an outpatient when you leave here.'

I attend one more session with him before I go home.

He tells me then that he will not be able to see me as an outpatient, he doesn't do that work. He refers me to someone else, whom he thinks will be good for me. I take his word for it because he has made me trust him. I am booked in for the following week.

I know that when next week comes around, I will attend as directed, and I will meet the new person: a man who has colourless hair and wrinkled skin, and smells a little

old. I will feel uncomfortable as he reads my file; I will wonder why I bothered to come.

He will shuffle the papers, and lay them down, and turn to me and say: 'Hmm. Perhaps you should know: I have a son with a disability.'

He will look over at me, and see the tears coursing down the flanks of my face, and he will not know whether they are tears of sorrow or shame or relief.

Then he will continue: 'My son was born blind. He's in his twenties now. When he was born, we were shocked, and my wife was devastated. The doctors couldn't tell us why it happened.'

He will prescribe anti-depressants for me, and will tell me that they take two weeks to take effect. They will be the old-style drugs that numb you and fill your brain with cotton wool, but let you sleep and quell your demons. And I will continue to see him each fortnight for three months.

On my final day at the clinic, a nurse has organised a walk to a patch of bush not far away. I am made to go, and I join a motley bunch that has gathered at the entrance. Headed up by the cheer-leading nurse, we form a straggling parade down the suburban street, then turn off into the reserve where we follow a track through gums and native shrubs to a picnic area. The sky is grey and heavy, and I feel bereft. I want to be with my husband and my daughters now, not here, with these people.

When we return, I pass the Picasso women once more on my way to my room. I try to ignore them, but my gaze is drawn back to them.

They call to me, like sirens. They beckon me into their frames, and hail me to take up their story. But I resist. The story they give me will extinguish me: it will deny my body and carve my soul into a shape I do not recognise. The more they hail me, the more determined I am to hold back. I am beginning to piece together my parts again, but their gazes threaten to rip open the clumsy sutures. I want to sew my parts together in a different way.

With a huge effort I turn away from them.

That afternoon I pack up my things and wait to be picked up: I am ready to come home.

# ***Identity***

*July 1990*

I have ... shown the x-rays to our paediatric neurosurgeon, who agrees that there is no cause for alarm and that the early closure of the anterior fontanelle is just a variation on the normal...

I think that the overwhelming likelihood is that Amelia is totally normal and nothing further will need to be done.

*November 1990*

## **CT HEAD**

10mm contiguous axial scans were performed from base to vertex without contrast, with 5mm sections through the posterior fossa.

There is asymmetry of the posterior fossa with some flattening of the right occipital bone. The lambdoid suture appears open at the base of the skull however, it appears ill-defined on the right in it's [sic] middle and superior portions, this is suggestive of partial closure of the sutures in this region.

Intracranially, there is prominence of the ventricles and subarachnoid spaces. The right lateral ventricle in particular is markedly dilated and there is marked prominence of the sulci overlying the frontal and parietal regions.

*November 1990*

In summary, she was a 7/12 girl who has microcephaly and a developmental level of about 4 months. There were no clues on examination to explain the possible course [sic], but a cerebrovascular insult late in pregnancy or intrauterine infection are possibilities... We have organised a few investigations including urine metabolic screen, torch titres, chromosomal analysis, audiometry and ophthalmological assessment.

*April 1991*

Amelia is a 1 year old girl with microcephaly, global developmental delay and an umbilical hernia...

*February 1992*

**BACKGROUND INFORMATION**

Birth weight 3425 gr  
Head circumference 34 cms  
Length 51 cms  
Apgars 9 & 9 at 1 and 5 minutes

Neonatal period uncomplicated. At 2 months when she was checked for her umbilical hernia. A small anterior fontanelle was noted - initial diagnosis of Craniostenosis was made but Catscan showed primary cerebral Atrophy with large ventricles.

*May 1992*

Amelia was born as a cephalic presentation, and at birth she was noted to have an asymmetrical cranial shape. She was breast fed for seven month. There were no obvious feeding problems. The mother denied having any bleeding, or exposure to teratogens during pregnancy. She did have an acute asthma attack within one week of conception which was treated with intravenous corticosteroids, and a single chest x-ray was performed at this time.

The parents are non-consanguineous, and there is no family history of developmental disability.

Amelia underwent TORCH serology, chromosome karyotype, CT scanning, urine metabolic screen, and ophthalmological assessments, prior to my consultation...

None of these investigations have identified a causal reason for Amelia's problems.

*December 1993*

Thank you for referring Amelia with gastro-oesophageal reflux and cerebral palsy ...

*March 1994*

I have reviewed this little girl's x-rays and they are reported as normal. However, I wonder if she has a slightly larger vestibular aqueduct in both ears ...

### **CT BRAIN SCAN**

The brain was scanned from base to vertex before and after injection of non-ionic contrast.

There is marked dilatation of the entire right ventricles and mild to moderate dilatation of the left lateral ventricle with moderate dilatation of the third ventricle. The fourth ventricle is not enlarged...

There is also an enlarged cavum vergae. No other abnormality.

*April 1994*

Thank you for seeing this child who has congenital sensori-neural deafness, marked developmental delay and features of cerebral palsy. She appears to be evolving into a left spastic hemiplegic form of CP. However to date there has been quite marked hypotonia and some ataxia.

*April 1994*

Thank you for seeing this delightful girl ...





## ***Strange country***

The stars up here are brighter, Eliza had thought. The air is clearer, the weather cooler, and the views over the blue-green bush seem to go forever.

Eliza and Paul decided to move to the Mountains to give themselves and their daughters a new start, but a couple of months in, they were not so sure. They missed that global village of neighbours and the shopping centre where you could dine out on Japanese and Lebanese, and everything in between. There was one Chinese restaurant in their new town; it would be another five years before a Vietnamese bakery opened, and three more after that before they could eat Thai. There was not an ethnic kid to be seen in the kindergarten class at the local school where they enrolled their eldest daughter, Rosie. And the bloke next door looked like he had just stepped out of an old bush yarn.

But their house backed onto the bush and the air hummed with birdsong. Green and orange lorikeets perched on their deck rails and sulphur crested cockatoos squawked from the treetops. Lyre birds made their nests in the gully behind them and scuffled their way through the compost heap at daybreak. Pesky possums clattered across their roof at night and wallabies thumped through the gum trees. A willow in a corner of their yard spread its languid arms to make a play house for Rosie. The bush was a living breathing haven of growth and renewal.

They sold their house just before Christmas 1991. They moved in January, and on that day when the truck was loaded up and the little house was emptied of them, Eliza didn't want to go. She didn't want to leave the lovely home they had made, but in the six and a half years they had been there, its transformation had come full circle: from derelict to joyful and then to bleak. They needed to make that break, she understood, to move on from that place where they had found themselves. They needed change. Her heart, though, was heavy with loss.

Paul drove the truck with his brother John, the family dog restless on the cabin seat between them. Eliza took her daughters in the station wagon, belted into their booster seats in the back, surrounded by mounds of last-minute packing. By the time they left

the plains rain was falling in sheets. When they arrived at the new house, halfway up the mountains, Paul and John had already begun to shift in the furniture, trudging through the rain, up the stairs with their heavy loads, their muddy boots leaving thick tracks across the carpet. The bushman next door was watching through the slats of his venetian blinds.

That night they ate pizza on the floor of the big downstairs room. Dog-tired and wet, they struggled to organise beds for their bewildered girls. When the children were finally asleep, they drank beer by torchlight because they couldn't find the light switches that were hidden somewhere behind the curtains.

The new timber house was so big they often lost each other. But unlike their old double brick home, it felt curiously insubstantial. The walls seemed thin, no thicker than skin. They needed work done on the timber deck, and when a builder came to quote, he refused to take the job on. He said to Eliza, 'Good luck to you. This place is hanging on a wing and a prayer.' When his ute disappeared down the driveway, she rang Paul at work, and tearfully told him what the builder had said. There was a long pause as he digested the news. 'Just call someone else,' he said. If the builders they finally hired felt the same way, they never let on.

Eliza contacted the local disability department that the hospital in Sydney had referred them to. She drove Daisy down the mountain to the weekly play group, the Western Sydney group, where she found the other mothers foreign to her, stranger even than the multicultural women from the previous one she had attended. More ladies with clip boards came to the house; they sat on her lounge chairs and drank uncomfortable cups of tea, and asked her questions. A string of speech therapists just out of their degrees also visited, and held objects in front of Daisy's face, then told her that her little daughter was not making eye contact. She took Daisy to orthoptists and ophthalmologists and podiatrists. She lined up appointments with GPs and social workers and case managers. She attended hydrotherapy sessions and hearing clinics.

The days, if Eliza would admit it, were lonely. Paul's long commute meant that he was gone for the whole day and into the evening. Rosie was at school now, and she was not responding well to this new regimented world. The teacher told Eliza that Rosie was having trouble fitting in; she was too creative, the teacher said, and they

should try to find a different school for her. Eliza told Paul, and they shook their heads and wondered about how small that box called normality was. When they had first met the principal they asked him how they catered for children with special needs, in case Daisy might go there in the future. ‘We don’t get much need for that up here,’ he said. ‘There’s more of that down on the plains.’

Eliza was mostly home alone with Daisy, feeling pressured to do hours of therapy, hours of rolling her reluctant child around on a giant plastic ball, hours of encouraging her to grasp objects she didn’t want, hours of making her watch her mother’s lips as they contorted around ems and pees and bees. Hours of blowing bubbles and happy clapping while Daisy stared blankly, and they both really just wanted to get out of the house. Eliza found an occasional child care centre, a cooperative where you could leave your child for a couple of hours, if you put in the same number of hours there caring for other kids in return. But she felt awkward, felt that no-one wanted to make an effort with Daisy, and they attended only once or twice.

As the weeks unfolded, she found two friends: a neighbour who had twins in Rosie’s class, who came over for cups of tea, who was strong and down-to-earth, and who accepted Eliza and Daisy without questions and judgements. Her other friend had a fragile child, born premature, in the same class; she was a nurse, and she knew how to look past Daisy’s disability and see her beauty. Most of the mothers at the school gate formed clans and sized up the value of potential friends for themselves and their children, and plotted over play dates and birthday party invitations. It was their very sameness that made Eliza sense so keenly her own difference.

On weekends they went bushwalking. They bought a guidebook, and packed a picnic and drove up the mountains to a new spot each Sunday. Paul carried Daisy in a backpack and Eliza held Rosie’s hand as she scampered along the trails. They found special places that they returned to again and again, places where waterfalls rushed over polished rocks and giant ferns draped their lacy fronds, where the leafy ground was dappled with sunshine, where they were alone and together. The bush beckoned to them, and not just on these outings. One morning they heard hammering on their front door while they were still in bed; it was the next-door bushman, informing them

that Rosie was out wandering through the bush at the back in her pyjamas. She was going native.

But the bush was dangerous, too. Living on its edge, they understood its power: it was always encroaching, advancing to reclaim its lost territory. On the cusp of the ridge, their house-and-garden block was a thin veneer pasted on to the ancient tract below, ever vulnerable. Termites, leeches, spiders, bush rats. Branches that groaned and creaked, that cracked free of their tall mother-trunks and crashed across the yard. Torrential rains that washed away the topsoil. And fire, a hazard they were yet to experience.

Six months after they moved, another country unexpectedly opened up to Eliza. It was a wide open field with a lake and a cluster of low-slung buildings that squatted on a hilltop. It was a university faculty, unlikely in that place at the base of the mountains. There had been a newspaper advertisement that fitted her so oddly and completely that it seemed to be written just for her. She read it over and over until the words swam, then she cut it out and placed it on the table in front of Paul. He looked up at her with his eyebrows raised. 'Go for it,' he said. If she got the job, he said, he would take leave from work and do the home shift. The long commute was wearing him down and he was tired of the public service job he had done for so long.

She drove down the mountain for the interview and parked in the car park that was almost deserted in the wan winter sunshine. Two of her old bosses were on the panel; they had known her when she was a bright young thing. But they didn't know her now, and as she sat primly and answered their questions, she felt like an imposter. She was surprised when a couple of days later she was offered the job. She was initially jubilant, but then the doubts came crashing through, about neglecting her girls, of relinquishing Daisy even to Paul, and of excavating a vestige of her old self that could take up this new identity with some conviction.

Later, she would recall the effort it had taken. There were lectures and course notes to put together, and admin, and technology that seemed to have rapidly advanced while she was elsewhere. There was the trek up the steep hillside from the train station with heavy bags because Paul needed the car. There were the students, lovely, needy, greedy, who pushed and pulled at her. There were the faculty staff members

who hung out in cliques, and fought their territorial wars, and built the fortresses of their careers in the rows of offices in the buildings on that wide empty plain. But most of all, there was the separation from the girls, from home, a cleft that lay her open and vulnerable. One night she dreamed that she was outside the house in the dead of night, the cold wind blowing through her nightdress. She was trying to get inside, thumping on the door, cupping her hands around her face against the black windows and struggling to see inside, but there was only darkness. She had been locked out.

She roamed the landscape of her life in various guises, always in transit, always alert to the next threshold that she would have to cross, that would require something different of her: teacher, colleague, friend, wife, mother, disability tribe member. Sometimes the boundaries broke down, and the edges blurred, or the shapes that butted up against each other were pushed too hard, and cracks appeared. On the day of her first lecture to three hundred students, she glanced down as she stood on the podium and saw that she was still wearing her old bush-walking joggers, the ones she wore to climb up the muddy hill from the railway station. Another time, sick with a gastric bug, she had left the university early, and when she got home, she saw smoke rising from the compost heap that had rotted down too well at the bottom of the garden. She hosed it over before lurching into the bathroom.

Paul took up the home shift enthusiastically, but he soon found that fathers were rare creatures on the tour of therapies and doctors' appointments. People in the street assumed he had been made redundant; plumbers and pharmacists made him offers of shady deals in pyramid businesses. Instead of taking Daisy to hydrotherapy, he took her on trips to Warragamba Dam and Megalong Valley, listening to blues music in the car and rambling around the bush with a packed lunch. He managed to escape the clutches of the disability services without guilt and with impunity, unlike the mothers like Eliza who accepted these tiresome rituals as penances. But by the time his year at home was up, he was looking forward to reconnecting with the adult world.

With both of them at work, they needed to find child care for their girls. The local centre agreed to take Daisy for two days per week; the staff were well-meaning but no extra help was offered. Eliza felt miserable every time she dropped off her tiny girl. On those days Rosie attended the out of school hours centre next door; months after,

Rosie told her parents how she could see Daisy through the cracks in the paling fence, sitting by herself in the yard, rocking back and forth. This made her feel sad, Rosie said. Later, Eliza would wonder why she hadn't been given some special support for Daisy; she had found out that this was available for children with special needs. Eliza still had to learn that you had to know what was out there, and demand it; you couldn't expect it to just drop into your lap.

For the other three days, Paul and Eliza set about finding a nanny for Daisy, someone who could also take Rosie up to school and pick her up in the afternoons. They advertised in the local paper, contacted churches and universities, and registered with the Commonwealth Employment Service. They wanted someone who was kind, who had experience with young children, who was interested in disability and was committed to helping Daisy. They promised to pay above the award rate.

They scheduled the interviews on a Saturday afternoon. One of the three applicants was outstanding: she had worked with young children with disabilities and she lived close by. But all three wanted to make a deal with them: they were interested in the job and the wage, but they wanted to be paid in the hand so that they could keep their unemployment benefit. Paul and Eliza explained that this was not an option, as they wanted everything to be above board, with insurances, to ensure the safety of the worker as well as their children. Their preferred applicant finally agreed to these terms, and Paul, who was still at home, took her on the rounds of Daisy's activities as orientation, and provided her with keys and a spare booster car seat. On the evening before this woman was due to start, they found the car seat propped up against their letter-box, and the keys in an envelope inside it. They never heard from her again.

In desperation, Eliza asked the co-ordinator of Daisy's child care centre if she knew anyone who might be suitable. The woman thought for a while, and looked through her files. Then, a little tentatively, she gave Eliza the name and phone number of the only person she could think of. Eliza dashed home and made the call. It was answered by Kim: Kim, who was to become a lifelong friend; Kim, who some years later, when Paul joined the Catholic Church and Daisy was baptised there, would become her godmother. Kim was one of the glittering treasures unearthed in that strange country.

When Daisy was three years old, she learned to walk. She took her first tottering steps in a brand new pair of clunky orthopaedic shoes. She plodded across the grass, through the garden, down the street, her face crinkled in concentration as her feet connected with the earth. She even learnt to bushwalk, with someone's patient hands always there to guide and steady her over the uneven ground.

Not long after, she was diagnosed with a hearing impairment. Eliza and Paul had been worried about her hearing for some time. They had taken her for hearing tests, in which she was meant to push a button when she heard a sound so that a clown would appear behind a darkened window. But Daisy could not press the button, and she wasn't interested in the clown, so the tests were useless. Also, Daisy was particularly distressed by some sounds, such as shouts and cries, aeroplanes and sirens, and they needed to know why. Paul took her across the city to an expert in children's hearing, and she underwent electrocochleography, a procedure that measured the functions of her inner ear and auditory nerve. She was found to have a mild to moderate hearing impairment with recruitment, which meant that although some sounds were out of her hearing range, others were distressingly loud. News of this disability came oddly as a relief to Eliza and Paul, because it brought the promise of remediation: Daisy could get hearing aids, which would improve her hearing and enable her to develop language.

With the new hearing aids came intensive speech therapy: there was a window of opportunity, Eliza and Paul were told, for Daisy to catch up, to use the plasticity of the developing brain to make the necessary connections so she could learn to speak. Daisy hated the hearing aids, and persistently pulled them out of her ears. In the early days, before they found ways to keep the hearing aids in place, they were always disappearing. On one of their Sunday excursions into the bush, the family hiked down a steep hillside, Daisy in the pack on Paul's back, to a watercourse where they picnicked and paddled. When they reached the top of the cliff, ready to go home, they realised that one of the hearing aids was missing. With a shrug of his shoulders, Paul turned around and clambered back down the mountain alone in what seemed like an impossible mission to retrieve the hearing aid. But less than an hour later he returned and grinningly presented the aid, which he had managed to locate along the creek's sandy shore.

In a stroke of luck, a new preschool for children with sensory disabilities was opening at the beginning of the following year in a suburb close to the university. It was 'reverse integration', which meant that it was primarily for disabled children, but other, 'typical' children could also attend and learn alongside them. A man from the organisation came to their home to assess Daisy for eligibility. He interviewed Eliza, and filmed Daisy at play in the back yard, then took his notes and tapes back to the Committee for consideration. Weeks passed, and finally they were notified that Daisy was accepted for a five-day per week placement. Eliza and Paul were excited: Daisy would be getting the learning opportunities she so desperately needed.

At the end of that year, their second in the Mountains, fire struck. The main blaze started high on the western fringe of the range, then joined with smaller outbreaks and came roaring down the great river valley. It climbed the ridges to the northwest of the town, and advanced eastward. Smoke hung in grey swathes, obliterating the sun, and fire trucks lined up on the high ground along the arterial road. Everywhere men were hosing down walls and filling eaves with water, while women gathered children and packed up precious belongings. Eliza's sister arrived and took the two little girls back to the city to stay with her. Then frazzled firemen were racing from house to house in their street, instructing those who remained to evacuate. Paul was determined to stay; he couldn't bear to risk losing this home of theirs. Eliza felt torn between the desire to be there with him, and the need to flee.

At the last moment, just as the wall of flames was cresting over the closest ridge, the northwesterly wind changed to southwest, taking the fire off on a new trajectory. It skirted the town then crossed the arterial road further north, between the main settlements, and struck the dozen or so houses on that sparsely settled stretch. According to reports, the fire was over thirty-two kilometres long at that stage. In the days that followed, everyone milled about: they had been lucky, their homes had been spared, but the whole area – many, many square kilometres of bushland – was empty of life, and the charred stumps of the great gums stood smoking still.

The local papers reported that a combination of causes was responsible: deliberate arson, negligence, and lightning strikes from dry thunderstorm activity. Human fault, nature, or both. There would be forensic investigations, inquiries and reports. The



people of the town were safe, but they had been humbled, at least for a short while. Things had gone out of control, and there was nothing anyone could do.

On the day in January when the new preschool opened, Eliza and Paul waited with Daisy outside with the other nervous parents and their children. Along with colourful clothes and big smiles, most of these children wore hearing aids or thick glasses with eye patches: their badges of belonging. The mothers' eyes ran over each other, over the children, craving connection, while the fathers hung back, arms folded across their chests or clasped behind their backs, inspecting the building and grounds. When the doors opened and someone ushered them inside, into a large light space, purpose-built and equipped for these small people and their disabilities, a tiny voice piped up from behind Daisy with 'Look, Mummy, she's got a wobbly walk'.

Daisy loved the book corner, and the nascent garden with its clumps of blue plumbago and winding paths that overlooked a lake. She loved the staff, especially the young ones who had names like Bridie and Annaliese. She joined in with the songs and games, she ate her lunch at a long low table with all the others, and she took part in the speech therapy sessions that were built into the day's routine. She was invited to birthday parties on the weekends, where Eliza would cajole her into watching performing clowns and eating cake. Eliza, too, looked forward to her daily encounters with the other mothers, who were young and passionate about their children's education.

A couple of weeks into the term, the director phoned up and organised a meeting with Eliza and Paul. She sat them down in her office and assumed that smile – a mixture of kindness, pity and superiority – that Eliza knew only too well. She told them that Daisy could not continue to attend the preschool five days per week, that the school was designed to cater for children with *sensory* disabilities: hearing and vision impairments, not *intellectual* disabilities like Daisy's. Daisy would be able to attend three days per week, but she could not allocate any further time to her because she required too much staff time, and there were other children who would benefit more from the program. Eliza and Paul looked at each other, agog. But Daisy was assessed and selected, they protested; she has a right to attend five days, as agreed. The

director's smile tightened as she shook her head. I'm sorry, she said. The decision has been made.

They sat in the car outside the preschool. They were angry, but their anger was tempered by the awful message delivered by the director, that Daisy was not good enough for this special preschool. She had a hearing impairment, like many of the other children in her class, but unlike them, the hearing aids and the speech therapy had not helped Daisy to learn to speak or sign. Perhaps she would never be able to communicate in those ways. In the hierarchy of disability, they came to realise, Daisy was placed somewhere near the bottom. Perhaps they had to be grateful for the three days that she was welcome – or tolerated – there.

This new development affected not only Daisy, but the whole family, and especially Eliza, who was working full-time at the university. Now Daisy would be home two days per week; she no longer had her place at the local child-care centre, and Kim, who had cared for her with such devotion the previous year, had found another job. But Kim, with her reservoir of love for Daisy, agreed to reshuffle her workload so she could look after her each Monday. That left Tuesdays to Eliza.

On the day that she spent at home with Daisy, Eliza told her colleagues it was her working-at-home research day, but there was no research to be done with her demanding little daughter around. Instead, she headed down to the study at 9.30pm and worked through to 3.00 or 4.00am, and grabbed a couple of hours sleep, before springing up to organise the girls, drop them off, and front up for a 9.00am lecture the next morning. The preschool kept very strict hours: no child could be left before ten to nine or after five past three. It took her ten minutes to drive from there to the university, and she always seemed to be teetering on the limits: on the mornings when she had a nine o'clock class, she would arrive breathless at five past, and when her afternoon classes finished at ten to three, she would have to dash out and disappear like a restless spirit.

By the middle of that year, Eliza's shape had begun to shift in another way. Her body pushed at its boundaries with the burgeoning form of another baby. She was tired, run dry by her relentless routine, but she was also exhilarated. When she told Paul the news of the baby, he was tearful with hope and joy. Their third daughter was

born on New Years Day; Poppy, as she was called, was born in her caul: a lucky child.

Poppy's healing presence touched them all. Eliza spent a year at home with her baby: a year of wonder, in which she felt the charred pieces of herself renew. Paul, too, expanded with pride and fresh promises. At first, Rosie and Daisy were unsure about their new sister: Rosie was reluctant to share her parents' resources of love, and Daisy, who had just started at school, was overwhelmed by so many changes. But their lives expanded to accommodate Poppy, and they came to appreciate the richness that she brought them all. At the end of that first year, with enormous reluctance Eliza returned to work, to that other country and the demands of that other self.

The following years brought growth for each branch of their family. Daisy left that first school and started at another, a long bus ride away down in the city, where she belonged and thrived and blossomed into her best self. Rosie went to an opportunity class and then an academically selective high school, places where she was no longer considered too different. Poppy gambolled through her milestones and emerged as a being almost too determinedly perfect. Paul felt the call of the spirit, too long held captive, and joined one church and then another, where he was drawn to the songs and rituals and dreams of peace. For a couple of years, Eliza fought her yearning to savour every moment with her youngest child, but eventually she left the university to be with Poppy and to work from home.

Yet those years also brought shadows and deep pain. On a rainy winter's day, Eliza's neighbour with the twins would die in a car crash on the western highway that sees too many deaths, and her daughters would be left motherless. Paul's beloved brother, John, would be found dead in his small flat, alone, after an overdose of heroin, and Paul would spiral into deep grief. Eliza's father would contract a mysterious illness in the Philippines and die in a poor hospital before more help could reach him. For months afterwards, Eliza would see his face among the crowds at shopping centres and cafes.

By the middle of December 2001, early in the summer season, fires had already broken out in the Blue Mountains, caused by dry thunderstorms over the Great Dividing Range. The community was uneasy, its collective memory stirred, and

bushfire plans were activated: roofs and gutters cleared, leaf litter banished, eaves filled with water, valuables secured. Smoke clung to the summer air, pale and distant at first, but gathering darkly as blazes erupted on the surrounding ridges and began to advance towards the town. A couple of days before Christmas, the bush to the east of their town ignited, and the voracious wind drove it down to the edges of the towns below, along the edges of the highway so that the road signs buckled and melted and squawking cockatoos fled down onto the plains. Then the wind switched direction and brought the raging blaze back up with gathering momentum until it swept into the gullies just beyond the street where they lived.

On Christmas Eve, a state of emergency was declared in the mountains, with five massive fires and countless smaller ones breaching containment lines. Five hundred fire-fighters had been in battle mode for over a week. The smoky air was freckled with charred twigs and leaves, blown in from the fire-front. Paul's train from the city was the last to make it through that evening, flames leaping along either side of the railway track, and hundreds of workers had to find other ways of getting home to their families for the holidays. That night, from their deck, Eliza and Paul could see the red glow of fire just half a kilometre away, licking at the dark and taking with it three homes in the very next street.

On Christmas Day, Eliza's sister and mother drove up from Sydney. The main road had been blocked, but even on the detour the verges were burning. It was not much of a Christmas lunch, and they left soon afterwards, taking Daisy and Poppy with them. Rosie, turned warrior, refused to leave. The drone of water-bombing helicopters filled the air, dumping their payloads onto nearby targets. On Boxing Day, a crowd gathered at the end of their street to watch the spectacle of a plant nursery on a neighbouring ridge exploding. Fuelled by chemicals, a massive orange cloud mushroomed into the greasy air and sent them all gasping.

The wind changed again, and a day or two later the fire was in their gully, on their doorstep. Fire trucks lined their street, and under the watchful eyes of fire-fighters the burning went on, clearing out a hundred years of dead wood and compacted leaf litter. A team of men made camp in their yard that night, sleeping in shifts and keeping vigil as the flames yapped at their back fence. Eliza took coffee and toast out to them the next morning, and when the team thought the fire had moved on, they broke camp and relocated further up the street.

A couple of hours later, Eliza begged Paul to go out for lunch in the town. Their driveway had been blocked by fire trucks for three days and they hadn't been able to get the cars out; now they finally could. But Paul refused. He sat staunchly working at his desk downstairs while Eliza fumed. An hour later, his obstinacy paid off: through the window he saw a flare ignite in a tree just outside their yard. It was a spot fire, gaining breath and heading straight for the three pencil-thin turpentine trees alongside their timber home. He bounded outside and grabbed the hose, and yelled to Eliza to get help. She ran into the street; the fire trucks had all disappeared now, so she shrieked and banged on someone's door, and a posse quickly assembled with buckets, and everyone ran down into the yard. The neighbours on both sides had already heard the call, and like Paul, they aimed long hoses at the flames that were skittering up the bone-dry gums. The helpers filled buckets from the children's paddle pool in their yard that was brimming with water in readiness, just in case, and they passed the buckets along a chain to the last one, who doused the undergrowth while the hoses reached up into the trees.

It took them an hour and a half to put the fire out. Afterwards everyone lay on the grass, exhausted but triumphant. When the helpers had all picked themselves up and returned home, Paul and Eliza and Rosie filled their buckets and went into the bush and threw water over the embers that were still steaming to prevent further outbreaks. It was black and desolate down there, emptied of life, and amongst the smoking ruins they found the charred carcasses of bush rats. Rosie was sobbing now, for her beloved country.

Their town was a war zone, cloaked in smoke and dark as winter. Everyone looked dazed, otherworldly, as if they had all landed somewhere impossible. The main street was grave and ghostly, but people everywhere were hugging each other, crying, laughing even, reuniting like refugees. In the thick air, their faces all looked the same; their shared fears had painted out all the differences. Eliza caught her hazy reflection in a shopfront window, and ran her fingers over the skin of her face, still gritty with ash.

They called that week Black Christmas, and twenty-five houses in their area went up. No human lives were lost, but there was no accounting for all the wallabies and possums and lyre birds that perished. In the days that followed, signs were erected in every street, thanking the fire-fighters, and appeals were set up to raise money for

those who had lost their homes and possessions. By spring the bush in their gully had already begun to shoot green. New growth pushed upwards, out of the charred ground, and normal life resumed. Until next time.

## ***Presentation Day***

Bright white socks and polished shoes. Uniform freshly pressed. Hair brushed, swept up into a ponytail high on the crown of your head. Mouth and hands wiped clean. Hearing aids carefully fitted. Then, a toot from the bus in the driveway, and I grab your backpack and sing you slowly down the stairs, buckle you up and kiss you. ‘We’ll see you later,’ I say. I wonder just how long you can stay this neat and tidy.

It’s Presentation Day, Millie’s first. A letter came last week, inviting us to attend because she’s receiving an award. It’s a special day, and big sister has been granted the day off school to come along with baby and me.

We arrive early. I take an aisle seat near the front so I can park the baby in the stroller by my side. Big sister sits beside me, watching the crowd spill into the hall. It’s a mixed bunch here in this mountains town: bare-footed hippy couples with grubby toddlers, public servant commuters, and Seventh Day Adventists. The students file in and sit cross-legged on the floor at the front. The head teachers and important guests make their way to seats on the stage. Lastly, the children from the Special Unit come, pushed in wheelchairs, or led by their teachers, cajoled and quietened and safely installed near the big side doors, which are then clamped shut.

We look for Millie. Our eyes scan the hall, across the tops of heads, seeking out that white-blond ponytail. ‘Where’s Millie?’ big sister whispers, her brow furrowed. ‘I don’t know,’ I shrug.

Then a heavy-handed chord and the piano plods out the National Anthem. The crowd rises obediently. I still can’t see Millie. Where’s Millie?

Speeches and songs, and the scuffling of ragged toddlers under chairs. Big sister is getting restless, and starts stubbing at the floor with the toe of her shoe. ‘Where’s Millie?’ she asks again and again, each time a little louder and more insistent.

The Principal announces that the presentations will begin. The Special Unit children will be first, he says, so then they can all leave *quietly* through the side doors and go back to their classes. But still there’s no Millie.

The Head Teacher of the Special Unit takes the microphone, speaks, and a boy is wheeled out to the front. Someone props a certificate on the tray of his wheelchair. Next, a little girl is prodded by her teacher to go forward, but she's busy flapping her hands, and she needs a second call.

A moment later I hear it, loud like a summons, my daughter's name: 'Amelia Davy'. Then: 'special award for...', it's for something, but the words skitter past me. There's a sound like creaking metal, loud, and a rush of air, and the big side doors fly open. There she is, there's my Millie in the doorway, and she's screaming. She's pushed from behind by Mrs L., her teacher, who shoves her forward in short bursts to the front of the hall. She's standing there so small, her face crumpled, her cries ringing out over the heads of the children and their parents and into every corner of the building. Then someone passes a paper, her award, to Mrs L., who tucks it somewhere as she swivels Millie around, and takes her by the arms, and pulls her back out through the open doorway, into the outside, with Millie wailing all the while, and the big side doors go clanging shut behind them.

It's quiet in here now, a shocked, dull silence. Big sister is crying softly, the baby too. I stand up, I rise above the seated crowd, I take my daughter's hand, I push the stroller with my crying girls down that aisle, right across the front of that hall, past the gawping parents with their rowdy toddlers, past the rows of cross-legged children, past the teachers and the guests, and past the Principal and the Special Unit Head. I rattle those big side doors and prise them open, and a draught of cold mountains air releases into the hall. Then I take my girls and leave, and let those doors swing wide on their rusty hinges.

Aurora says Millie is the cutest girl in the whole world. She brings Millie gifts of teddy bears and tapestries she has worked all by herself. She's in Year 5, and she comes over to the Special Unit most days at lunchtime with two friends, and they take Millie out into the playground. They are Millie's buddies. They invite her to their birthday parties and they don't mind that her hands are always damp because she puts them in her mouth so much.

Not long before Presentation Day, I invited Millie's buddies to a Christmas party at our house to thank them for being Millie's friends during her first year at school.



Millie wore her red Christmas dress and a Santa hat, and we set up the table under the Chinese elm with party food and drinks. The girls played games and won prizes and hugged Millie.

Millie and I drove them home afterwards. But they sat in the back and whispered together in low, serious voices. 'What's up?' I asked.

Aurora began nervously. 'There's something we want to tell you,' she said, 'but we don't know if we should or not.'

'Oh,' I said, 'I'm sure it will be okay to tell me.'

'Well,' Aurora said, 'it's something that happened while you were away.' (A couple of weeks before, we had taken our girls for a week's holiday during school time.) 'We were at the Special Unit, and Mrs L. was there, and she was jumping up and down and clapping her hands a lot.' A pause. 'She was saying, umm, she was saying, "it's so quiet, it's so peaceful here without Millie". She said it lots of times.' Silence.

Then one of the other girls, Caitlin, said, 'We didn't know if we should tell you. But we thought it was really bad.'

'You've done the right thing, girls,' I said. 'Thanks for telling me.'

Then the three girls in the back were free. They sang songs to Millie all the way home.

I remember back to Millie's very first day at that school. Hot, as the first day of the school year always is, and me flapping and flying about, running after clothes and bags and lunches, with the clock ticking away. It was a feat of organisation: Millie starting kindergarten in the Special Unit class further up the mountains, big sister now in Year 3 at the school at the top of our street, and then baby, just four weeks old, to be cuddled and fed and changed amidst the breakfast rush and the helter-skelter.

I told Millie many times that she was starting big school today, but I knew she wouldn't understand. She doesn't like change; it puts her into a fog of uncertainty that lifts only as she slowly absorbs the newness into the routine of her life. She has to take it all on trust.

We bundled into the car and up the street, and dropped big sister at her school gates, then we swung onto the highway, and drove twenty kilometres west. We parked in a side street close to the Special Unit which was in a corner of the school grounds, and I struggled out with Millie, and backpack, and baby in the car capsule. Millie was wearing new orthopaedic shoes, big black ones, and the checked uniform that Grandy had made because there wasn't a size small enough in the shops.

It was busy and noisy, but Mrs G., the kinder teacher, welcomed Millie warmly and ooh-ed and aah-ed over my new baby girl. Last year when Millie's father Peter and I had visited, baby was still just a large bump in my front. Then Millie began to flap, as she does when she's feeling unsure, but everyone was kind and the classroom was bright and cheerful. I stayed and talked with Mrs G., and met the other children, and watched as Millie did her best to settle in. They all sat for morning circle, and we sang some songs, and when I knew she was safe, baby and I left, and relief washed over me as we made our way back home.

I was back there at 2.45pm to pick Millie up. She was tired and her eyes had glazed over with too much going on, but she was okay. She looked happy to see me. But we had to move quickly, no time to lose, to get back to the school at the top of our street by just after three to fetch big sister, and we only just made it. The teachers told me it would take six weeks for the Special Transport Service to organise a bus to pick Millie up and take her home. So each day I packed the girls up and made the two round trips, eighty kilometres a day. I didn't know then that just two cranky phone calls from me to the Department would have got a bus to our door within a day or two.

But I had the chance to find out what was happening in Millie's life. Mrs G. loved all the children in her class, including Millie. She understood Millie's likes and dislikes, and how music was the key to her learning and to her heart. Mrs G. became my friend, and she came to the big party we held for Millie's fifth birthday. But Mrs G. had worked in special ed for many years, and it had taken a physical toll: three months later, the arthritis that was developing in her wrists and elbows became so bad that she had to give up her teaching job and retire.

After Mrs G. left, there was no-one to take her place. Casual teachers shared the job, one or maybe two days each per week, so that every day was unpredictable. Millie didn't love the new teachers like she loved Mrs G., and they didn't seem to understand her so well.

So when the bus pulled up each morning, Millie would cry, and refuse to walk down the stairs. Every night she woke around 2.00am, noisy and fretful, and she wouldn't go back to sleep before five. I tried to do most of the night shifts myself, singing endless songs through those bleak small hours, because Peter had to go to work early. But I had the baby waking in the night as well. When I passed a mirror and caught my reflection on those mornings, I wondered if that ghost could possibly be me. When I looked into Millie's troubled face, I felt pangs of guilt that nearly broke my heart.

I joined a group for mothers of children in the Special Unit, a support group convened by a social worker that met fortnightly in a church hall. There were just four or five of us, but we shared our secrets and our fears as we drank cups of tea. We told stories and joked about the things people said to us about our children.

Six months later, Millie's Individual Education Program meeting was due. The teachers told me that every child in special education had an IEP. They said that it brought together those people who interacted with the student, to plan the learning goals for the coming year; that it was child-centred and family-friendly; and that we all needed to work together, to achieve the best results for the child. They said that both parents needed to come, and they scheduled us in for a day and a time. They sent home questionnaires and forms for us to fill out beforehand. They said we could bring a support person with us, if we wanted. Peter organised to take the day off work.

There were seven people seated around the table in the small meeting room when we arrived: one casual teacher, a teacher's aide, the Special Unit Head, the Principal, the physiotherapist, the speech therapist, and the Special Ed Consultant from Area Office. They were all there to talk about Millie, who was back in her classroom.

They talked about Millie's flapping and tapping, and how she kept pulling out her hearing aids. They said she had severe communication problems that were indicative of autistic traits. They said her behaviour was often disruptive, and her general mood was deteriorating. We felt their seven pairs of judging eyes upon us. It seemed that the child they were talking about was not the same little girl we knew and loved.

They wrote down a lot of notes, and then they asked us if we had anything additional to raise. We looked at each other for a moment: we had agreed beforehand to bring up the problems that we felt were affecting Millie. I said that our daughter was unhappy, that she wasn't coping with all the changes in the classroom, that her behaviour had changed when Mrs G. left. Millie was sleeping badly and she seemed depressed, I said. Peter said she needed more stability in the classroom; there were too many different faces, and too many different styles of teaching and expectations of her. We asked them what they were going to do about it, if they were going to try and sort out the teacher problem.

I don't know who spoke next, who it was that told us that we shouldn't assume that Millie's mood was related to what was happening in the classroom. But I remember the tone of that voice, and those measured, insistent words that put us in our place. I saw that Peter's face had clouded over. But the voice went on: 'You have to understand,' it said, 'that changes in mood and behaviour are more often than not developmental. That's how it is with these children.'

Peter stood up, and looked intently into the faces around the table. 'This is not about Millie,' he said. 'It's about you. It's the mood of the Special Unit that has changed, not Millie. You can't blame her for that.'

Peter never went to another IEP meeting at that school. I made sure a support person came with me to the next one.

These memories play across my mind like stones skipping over water: some seem to barely graze the surface, but the ripples they create fan out and intersect, making waves and casting shadows, moving in random paths that cut across time and space.

My memory skips now to some months later, during Millie's second year at school. It's the annual school fete, and our family heads west that Saturday morning, bearing trays of apple crumble that I've dutifully made for the cake stall. Most of the other families there are strangers to us, because we live so far from the school. But Aurora and her two friends spot Millie, and bound up to her. Millie is thrilled to see them. They want to introduce her to their parents, so they take her hands and lead her off, and we all trail after them.

The girls find Caitlin's mother first, and proudly present their precious little friend. I smile and make small talk, but this woman ushers me aside with a grim face. 'I'm glad I've met you, because I want to talk to you,' she says. 'Caitlin has been spending nearly every lunchtime with your daughter,' she continues, 'and frankly, I'm becoming very concerned. She's missing out on a lot of extra-curricular activities, like choir and sport. She should be spending her time doing things that are more beneficial to her education.'

My hands are shaking. I've never thought of my little daughter as a waste of time. 'I think it's Caitlin's choice to spend her time with Millie,' I say. 'But if you're worried, you should speak to the teachers. What happens at this school at lunchtime really has nothing to do with me.'

I was back at work this year, and so I couldn't get to the mothers' group meetings. I couldn't share this story with them, and turn it into a joke.

Then the last memory of that time leaps across the turbulent waters of my mind. The stone is so heavy now with the weight of remembering that it no longer skips, but sinks straight to the depths, and it's hard work to retrieve.

I walk with my two daughters along the warren of concrete paths that leads to the other side of the school, where the Special Unit huddles inside its high wire fence. The sound of children's singing floats across the dense air, from the Presentation Day celebration in the hall. My face is red and hot in spite of the cool breeze. Big sister and baby are quiet, as if they understand that this is serious.

I am still new to this. I worry that one day I won't be.

Beyond my own reflection in the classroom window I see Millie tap-tap-tapping a piece of lego against the pane. She is engrossed, and doesn't see me. Behind her I see Mrs L. seated on her chair, her back to us. There is no-one else in the room. The other children are still in the hall.

I'm outside the gate to the Special Unit now, and I take deep breaths to steady myself. Once I open that gate, once it squeaks to announce my arrival, I will have to go through with this. There will be no going back.

Big sister holds the gate open and I wheel the stroller through into the fenced enclosure that forms a kind of courtyard in front of the classrooms. We enter the hallway, and I pause for a moment before knocking on the classroom door. Millie is still tapping her lego over by the window and doesn't notice us. Mrs L. startles slightly and looks up, then she motions us in. Her face is a study in blankness: she must have known this was going to happen. I set big sister up on a small chair in the corner, with the stroller and baby beside her.

'What was that all about?' I ask Mrs L..

'What do you mean?' So calm.

'What happened with Millie over at the hall. Why wasn't she inside with the other children from the Unit?'

'We felt that she was going to be too disruptive. We felt that the less time she would be in the hall, the better.' It's that voice again; a different speaker, but the very same voice.

I rummage in my handbag and pull out the Presentation Day invitation, and wave it about. 'Is that what we were invited to? Is this what I brought these girls along for? To see their sister humiliated in front of the whole school?'

Mrs L. stares at me, her eyes glinting like pinheads. 'I can see that you're upset. But we had no other option, other than to exclude her altogether.'

'She has a right to be included,' I say.

But my self-possession falters, and it threatens to dissolve into a flimsy display of tears.

'Look,' I say, 'you just needed to have some music with you -- a walkman playing, or someone singing softly in her ear. As long as she has her songs, she's fine.' I look at her for some trace of understanding. 'I thought we had all talked about that.'

Mrs L. just shrugs. 'That was the decision that was made, and not just by me.'

Millie sees me now, and comes over. I hold her close. Mrs L. stares at me again, and I can see that familiar word spelling out behind her rigid gaze. It's a word that's never said to me but it echoes loud through the silent air. It's a word that marshals my wilful emotions into a kernel of cold determination: the word is 'denial'. They think I

haven't come to terms with Millie's disability, how 'bad' she is. They're right: I still believe in her.

I decide to play my last, my most dangerous card.

I tell Mrs L. what Aurora and Caitlin told me, that they heard her laughing and cheering because Millie was away from school for a week. I tell her that these young girls were shocked and distressed because they love and value Millie. I told her that I thought this was a bad example to set about attitudes to children with disabilities.

Mrs L. nods slowly, and I can see that she is trying to blink back tears, but several manage to slide down her cheeks. I don't think I meant to upset her, but then again, maybe I did.

She sniffs, and says, 'I'm sorry.' She tells me that it was the wrong thing to do, that she doesn't know why she behaved like that, especially in front of those girls.

I'm facing the window, and just then I see the Special Unit Head and the Principal outside, looking into the classroom. Their faces register indignation. They disappear, and a moment later the door swings open and they bluster in.

The Principal faces me, his voice tight with anger: 'Why are you upsetting this teacher?'

The Special Unit Head goes to Mrs L.'s side. 'What is this parent doing in here? Are you okay? Do you want her to leave?'

The Principal looks at Mrs L. 'You can make a complaint against this mother.'

But Mrs L. shakes her head.

'Well then,' he says sternly, 'I need to know what this is all about.'

I say to Mrs L., 'Do you want me tell them what this is about?'

Mrs L. sniffs and lowers her head, tears still wet on her cheeks. 'No,' she manages.

'If you have any problem at all, you should discuss it with the Unit Head or myself,' the Principal says to me. 'You have no right to distress a classroom teacher.'

'But,' I say, 'I believe the correct procedure is to speak with the relevant teacher first, before taking the matter further. Isn't that right?'

They nod.

‘I believe that Mrs L. and I have resolved the situation. Do you agree, Mrs L.?’ I catch her eye; she knows now that I am protecting her.

She nods.

The Principal finds a chance to exit. The Unit Head, however, circles about with her hackles raised. She sits down next to Mrs L., and she wants answers.

I give her questions, about the Presentation Day. I ask her why she thinks it was acceptable to treat Millie like that. By then the other children and their teachers are making their noisy way back into the Unit.

The next day I will phone the school office, and make an appointment to speak privately with the Principal. But now, I take Millie with one hand, the stroller and baby in the other, and with big sister, we make our way to the car. When I lift the children into their car seats, I notice with some alarm that the skin of my arms looks curiously thicker than it was just a few hours earlier.

2.00am, and your call wakes me. I fumble through the dark to your room, and feel my way to the bedside table. In the lamplight I see your hair tousled on the pillowcase, your sheets in disarray. You’re still crying, but softly now, as you rub your eyes and squint into the brightness. I tuck you up and kiss you, then turn off the light and kneel by the side of your bed. I begin to sing one of our favourite songs.

*‘Hush, little baby, don't say a word,  
Mama's going to buy you a mockingbird.  
And if that mockingbird don't sing,  
Mama's going to buy you a diamond ring.  
And if that diamond ring turns brass,  
Mama's going to buy you a looking-glass.’*

I don’t remember the rest of the words, so I sing these ones over and over, until finally you are calm and quiet, and breathing with a gentle rhythm. When I’m sure you are asleep, I lean over and whisper another line into your ear, a made-up one that becomes my promise to you: ‘And if that looking-glass breaks, Mama’s going to do whatever it takes.’<sup>3</sup>



## ***Exiles on Main Street***

It's hot, and so crowded here that it takes some time to find a square of grass where we can park ourselves. Children are everywhere: little kids, big kids, skinny kids, fat kids, noisy kids, quiet kids, fair kids, dark kids, plain kids, pretty kids. Kids with plaits and hats and freckles and ice-blocks running red streams down their forearms. Kids in speedos and bikinis and water-wings and kids wrapped up in towels. Kids laughing, crying, whimpering, shouting. Kids who are swimming and splashing and crashing and running and some just sitting.

Laura hops up and down while I unbuckle Millie and help her out of the stroller. I plaster sunscreen across their faces and shoulders and backs. Laura scampers ahead as I hold Millie's hand and help her walk slowly, tentatively, step by careful step, over to the baby's pool. When we've been in the shallow water for five minutes, Laura gets bored and jumps into the next-door medium pool. I make sure I can keep an eye on her while I swish Millie, who is like a squirmy fish.

When we've all had enough, we make our way back to our spot on the grass, through the bodies and bags and towels. A teenage girl, not one of the silly self-conscious ones, is watching Millie; she's not peering at her sideways, nor whispering behind a cupped hand to a friend about her, but just watching. Then she gets up and comes over.

Gee, she's cute, she says. What's up with her?

That's so refreshing.

Millie is nearly there, nearly up on her feet and walking all by herself. It will be the big new orthopaedic shoes that get her going soon: they will hold her ankles firm and keep her upright. But for now she's cruising around the furniture, holding on to the bookcase, climbing up, up on to the lounge chair.

I'm not quick enough.

*Crash!*

She's gone right over the back of the chair and onto the floor. She's screaming. I dash over and pick her up and cradle her in my arms: Where is it hurting? I ask, but she can't tell me so I pack her into the car and rush her up to the doctor.

I take her inside and tell the receptionist I need to see someone urgently. Millie is still whimpering in my arms. The doctor on shift comes out and we go into his room and he pokes and prods around Millie's body and head. He looks into her eyes with his special torch and says he can't tell where the injury is.

He asks me questions about her, about her disability. I don't like the way he inspects her, as if she is a curiosity. Then he sits back and begins to tell me a story about himself, about how he went to the UK in the late sixties and while there he spent time at the hospitals where the Thalidomide babies were. How it affected him as a doctor to see them. How tragic it was.

But I need to get help for my child, I say. I ask him what I should do. He tells me to give her some Panadol and come back tomorrow if she's still upset; he will check her over again then.

I park the car at the shops to get something quickly for dinner. In the street I see by chance Millie's physiotherapist from her Early Intervention program. I tell her what has happened. She carefully lifts Millie out of the car and sits her on a bench on the footpath. Then she looks over her, and sees that one of her ankles has begun to swell. She touches it very gently. Millie's response confirms that this is the place: it's a sprained ankle. She gets her bag from her car and bandages up the ankle nice and tight, right there in the street. Keep her off her feet, with her leg propped up if you can, she says, and she'll be fine.

I'm sitting in the Joan Sutherland theatre, or in a school auditorium, or in an RSL club hall. I'm at a school choir concert, or a dance extravaganza, or a drama performance, or a piano recital. I'm here to watch one of my daughters, who will be up there on stage soon.

All around me are parents who have come to see their kids perform. I see the mothers and fathers of Laura's or Gabrielle's friends, sitting in pairs and leafing through their programs, or with their heads bent together, talking quietly.

The seats on either side of me are empty. I squirm and shuffle in my seat, then I sit as still as I can. I'm hoping the lights will dim soon so that I no-one will see me, sitting here alone. Sometimes Gabrielle or Laura will be here with me. Sometimes, it's Peter here instead of me. But we're never together. I wonder what those other families might think of us, of our family, that we make such a poor showing.

It's hard to get someone in for these night-time events, to get someone we can trust who can bathe and feed Millie and go through her nightly routine. And it's expensive. But each year, we make sure we book a carer well in advance, and use our respite package to pay, so we can all get to the end-of-year school Presentation Nights together.

It's the first day of the school holidays, and the mall carpark is a jungle of stalking SUVs. All the disabled spots are gone, so we're stranded way out in the farthest corner. When we start our trek across the tarmac, I feel the familiar prickle of my defences, like hackles rising. People are everywhere, children milling with melted ice-cream dripping from sticky fingers, parents carping as they round up their broods and manoeuvre overloaded trolleys toward their cars. Everyone of them, it seems, is staring at us. I lead Millie blindly, avoiding the eyes that track us as we make our way down the stairs, one slow step at a time. We make it inside. Millie gives a loud whoop. I fumble for the iPod, and clamp the headphones over her ears. I look up, and there they are: all those watching eyes. I lift one of the headphones: Chocolate milkshake time, I whisper into Millie's ear.

We get to the donut shop, and I guide Millie into a chair at the only remaining table. Then I go to the counter and place our order. Millie stands up suddenly and sends her chair crashing to the floor. I dash over, fix Millie, fix the chair, fix the iPod.

Three sets of eyes belonging to three boys at the neighbouring table have found and focussed on Millie. The boys are drinking slushies. Their Nana tells them to sit still, be quiet, and don't make a mess, but she never says, don't stare. Across at the counter, a clutch of children and their parents see Millie as the support act to their drinks and donuts. A little girl is wearing a T-shirt that says, *I saw it, I wanted it, I got it*. She stands gog-eyed and points at us. Millie is quietly drinking her milkshake through her straw and crumbling her donut.

I need to be the perfect mother here. I need patience to manage Millie, to make sure her music is right, her straw is right, her chin is wiped. I need resilience to cope with the stares and the twee smiles that accompany our excursions into this small town where Millie has lived for 18 of her 20 years. I worry about my appearance, how I dashed out the door with messy hair, without make-up; I'd feel better if I was well-groomed, I think. Then maybe I could rise above it all.

A man with three kids and a couple of slabs of beer in a trolley parks at the donut counter. Suddenly a look of pure aggression comes over the face of the youngest child. This boy's eyes narrow, he snarls, he throws himself at his sister, and he pins her in a headlock. Then he punches her face. 'Dad!' the girl yells. 'Quit it, Dylan,' the father responds. Dylan lets his sister go and darts off across the concourse, his father chasing him.

But the three sets of young eyes at the neighbouring table are still all fixed on Millie.

I'm taking my three daughters to lunch at an art gallery near our home as a holiday treat. The gallery and its gardens are a popular spot on the Mountains tourist trail, and this place has – until now – checked out well as one of our better afternoon tea destination. As we walk through the gardens to the café, I think about how at home the sisters are amongst the bronze and marble nymphs and naiads that people the lawns and flower beds, with their long fair hair and pastel tops.

There's a sign propped up against the door of the café: 'Under New Management'. We find a free table inside and sit down. We sort out Millie's discman and earphones and apron, and make our choices from the menu. Laura places our orders at the counter, as another instruction bids us to do. We choose things that won't take too long to prepare, because Millie won't wait for more than a few minutes for her food. But she is delighted to be out with her sisters. She's on her best behaviour.

The café-woman brings our drinks. I ask her for a tumbler for Millie's milkshake. She sighs and fetches the glass, and soon she brings out our meals. I load up Millie's spoon between my own mouthfuls. When we are finished, we order coffees.

But Millie has had enough: she's past her tolerance level, and when that happens there is no option but to move fast. We're used to this: I ask Laura to cancel our

coffees, and to apologise; we will pay for them if they have been made already. In the meantime, I wipe over Millie's face and hands quickly while Gabrielle packs up her sister's bag.

The café-woman stomps over to our table, her face livid. She tells me I can't just cancel an order like that (why not? I ask). Then she lets fly: about our manners, and how we obviously don't know how to behave in a restaurant. I tell the woman to give me the bill so we can leave as soon as possible. She shakes her head scornfully and rolls her eyes.

When I am at the counter paying, she throws me a look of pure contempt and sneers. *Why don't you find some other feral café to go to?* she says to me.

My daughters are distraught now: Gabrielle sobbing, Millie wailing, Laura shaking with anger. We huddle together and make our way up the gravel drive to the car.

A few days after, I pull myself together and begin the complaints process. A couple of weeks later I get a phone call from the manager of the gallery complex. She berates me because her staff must now undergo disability awareness training. Are you serious? I ask her.

I'm in New Zealand for a week with my eldest and youngest daughters. I am visiting a good friend with whom I have taught on an online graduate program for many years. We are invited to the fiftieth birthday party of my friend's partner, at their home in a beach town outside Christchurch.

I am introduced to the sister of my friend's partner, who is also on holiday from Australia. I don't usually mention to strangers that I have a child with a disability. I would, of course, if that were the topic of conversation, but I'm not going to cast that line into the sea of small talk without a good reason. On this occasion I do, though, because I know that this woman runs a disability employment service in Victoria.

We talk for a few minutes, and she asks where I live.

The Blue Mountains, I say.

Isn't that a low socioeconomic area? she asks.

No, I say, the Lower Mountains where we live is pretty much middle class.

I hope you don't mind me asking, she says just a little hesitantly, but do you live in public housing?

A long pause. No, I own my own home. Why would you ask me that?

Because most families that have a child with a disability are economically disadvantaged, she replies.

I'm at a restaurant with a group of women, mothers from Millie's school, most of whom I haven't seen since her graduation, two years ago. We talk about some unfortunate changes at the school, how two of these mothers have moved their children to other schools as a result, and some of the best and most experienced teachers have left. The entry criteria, too, have changed so that our children, if they were starting school now, would not be eligible. They are too disabled.

Our conversation turns to other things: respite difficulties, problems with accessing equipment, the post-school world, and our need to be involved in the campaign for the National Disability Insurance Scheme. Two of the mothers are committed activists. We talk about scoliosis, and Millie's surgery, and how one of the mothers chose not to go through that procedure with her daughter. It was just too risky, she said.

Then I tell them a bit about my research into mothers of children with disabilities. I explain the idea of 'transformational coping' that is a current trend in the literature: academics claim that mothers become enriched through their experience; and the more disabled the child is, the more opportunity there is for this personal transformation. I ask them what they think about it. There's an uproar. That's way off the mark, they say, we wouldn't wish our lives on anyone. One mother reports that she had heard someone giving a presentation on this at a conference at Sydney University. I couldn't believe it, she says. I was so angry that I walked out.

The same mother, a well-educated, well-off woman, tells us what happened to her that morning. She parked her young daughter in her wheelchair in the driveway beside her car while she went back to lock up the house. When she came back a few moments later, a woman was standing there with her arms folded across her chest. Is this disabled child yours? the woman asked, and ranted at her about how neglectful she was. The woman threatened to report her to DOCS.

Oh yes, my friend says, I'm such a bad mother.

I'm at the local fruit shop when someone who lives in our street stops next to me. Is Millie still at home? she asks.

Yes, of course, I say.

Then why don't we see Millie's bus any longer?

Because Millie left school two years ago, I reply.

Why don't I ever see you around the shops? she asks.

I search my mind: maybe I just don't go shopping at the same time as she does.

I guess you don't get out much, she says.

I pick Millie up from her program, take her home for afternoon tea, and then we drive to our appointment with the local podiatrist, who was recommended by the special shoe shop in Parramatta. We need to get orthotics fitted for Millie's new shoes.

We sit in the waiting room, and Millie listens to music on her iPod. The podiatrist opens the door and her face, shocked first, morphs into an embarrassed giggle. She shows us in. I tell her why we are here and take Millie's shoes off. The podiatrist is tentative, doesn't want to touch my daughter's feet. She punctuates her words with more giggles. She tells Millie to do things that Millie can't do. She gets frustrated, and says it's no good, she won't be able to make the casts. She gets angry with Millie, a quiet, tight-lipped anger that turns her cheeks red and her lips white. I'm ready to walk out of there.

I think for a moment, and then I say, I'm wondering if you are the right person to do this for us. I tell her I would like her to try, because she was recommended to me, because I don't want to have to take my daughter all the way to the city to have her orthotics made.

She says that she doesn't see disabled people. (I thought, perhaps wrongly, that this is what podiatrists did.) But she does have some experience with them, she says: when she finished her training she spent a couple of weeks at a place for disabled people.

There, one client had to be held down by three people so they could take the moulds for her orthotics.

Then she asks me if I have other children.

For mothers like me, this a loaded question. Its subtext hits me like a cricket ball in the face: Is *this* your experience of motherhood? I answer her: yes, I have two other children.

Are they older or younger? she asks. It's not the kind of questioning that most mothers of 20-year-olds confront. My inner guards spring to attention. I translate it, not without a hint of paranoia: If this is the eldest, how could you dare to have others? If this is the youngest, was it a late mistake? One older, one younger, I answer.

I get Millie's shoes on and get out of there fast. In two weeks we have to go back there to pick up the orthotics. I only hope they fit.

It's a lovely sunny January day, perfect for a ferry ride. Peter and Millie and I drive to Parramatta and park close to the wharf on the river. Millie loves boats, and we stand with her on the deck as the Rivercat ploughs downstream and the wind whisks through our hair. We eat lunch in the Rocks and look at a shop full of handmade marionettes that jiggle and dance about when we move their strings. Then we make our way back to the Quay for the return trip.

The wharf is teeming with people. Many of them couldn't squeeze on to the boat that just left, so they are tense and frustrated and ready to fight for their right to get aboard the next one. The Rivercat docks, the gates are opened and the crowd surges dangerously. It's survival of the fittest here. We stand back and wait with a group of people in wheelchairs. A deckhand thinks to set up a gangplank for those who are less able-bodied, and I guide Millie up the steep ramp and into the cabin. Two seats are still free at the back, so I steer Millie towards them. A middle-aged man dashes past me and claims them first. Someone sees this, and generously offers me his own seats by the window.

Below, on the wharf, the deckhands are closing the gates: no more people are allowed on board. But Peter, who did not want to be one of the pushers and shovers, is still standing on the pier. I can see him speaking to the deckhands, gesticulating,



saying that his wife and disabled daughter are on board and he needs to be with them. The Captain leans out from the bridge and shouts, and waves him away dismissively. But Peter has the ferry tickets and the car keys. We can't, don't want to, go without him. I hoist Millie up, and we make our humiliating way through the crowded cabin and on to the deck. We have to get off the boat.

It takes us hours to get back to the car. We complain to the ferries, we even go on television about it. Then we get a letter from the Minister that says we should choose a day when there is less demand to travel by ferry with our disabled daughter.

I'm at the shops with Millie when we bump into a woman I haven't seen for some years. Our children, now grown-up, used to attend the same activities program for kids with complex needs when they were younger. I remember her as an exemplary mother, active in the disability community and an energetic fundraiser.

I ask her what her son is doing now, and she tells me he is living in a group home. Because it's so difficult to access supported accommodation, I ask her how this has come about. Then she opens up, and tells me how her husband passed away suddenly a couple of years ago, and she was overwhelmed, unable to manage alone the care of her son who has very challenging behaviour. She couldn't get respite care, and in desperation she went to the media. But by the time help was offered to her, she was at crisis point. She did something she never imagined she would ever do: when her son was in respite, she rang the relevant government department and told them she would not be picking him up.

She pauses for a moment. I shouldn't have done it, she confides, I'm no longer a good mother.

My older sister and her husband are visiting from the US, and we are planning a picnic day. My mother asks if I can organise for a carer to look after Millie at home that day because she will be disruptive. No, I say, Millie is part of the family and there's no reason why she shouldn't be included.

You don't understand, she says. You're used to Millie, but other people find it hard to deal with her. I find it very hard to be around Millie when she goes off and makes a lot of noise. It affects my hearing.

Then she tells me about a friend of hers whose disabled grandson is so bad that this woman won't visit her daughter's family anymore. It makes her too upset.

One afternoon a Catholic priest knocks at my door. I rush out onto the back deck and see him standing there below me. 'Go back!' I cry. 'Get back behind the gate!' My dog is barking frantically and running around the yard. Any minute he will be right there beside the priest, and he will likely land a nasty nip on that plump behind. My dog doesn't like strangers on his territory.

But the priest stays where he is, as if this warning could not apply to him. I run downstairs to the front door and usher him quickly inside. He is pink and sweating. Come and have a cool drink, I say, because I owe him this small mercy after his ordeal, and he follows me up the stairs.

I give him the drink, and look at him expectantly: why is he here? He reads my mind: I'm on my rounds, he says. I was just down at the S—'s house, and they told me that I should come up here and meet Millie.

Obligingly, I bring her out. Millie, this is a Father from the Church. He wants to meet you. But she spins on her heel and heads back to her bedroom.

We chat for a while and he asks questions about Millie. Then he looks straight into my face and says: Has anyone ever told you that you are a saint?

Millie is in respite this weekend, so I'm able to join some friends for a ladies' night out at a favourite Italian restaurant. Our lives have not been easy recently: one of our group lost her home and all her family's possessions in the recent bushfires; two are having major issues with teenagers; my marriage has disintegrated. One woman, a newcomer to our group, has a young child with severe autism. She has been invited along because a friend has been hoping to hook her up with me to help her access services.

When we've placed our orders, someone asks her how her son is going. She speaks from a dark place, through a thick cloud of negativity, about problems with his school, his doctors, his diagnosis. Then I say to her, I think I might be able to help you.

She pushes back her chair and gets up suddenly. She shouts: I'm going; I came out tonight to get away from my troubles, not to talk about them. We try to placate her, to tell her she doesn't need to talk about anything she doesn't want to. But she storms out of the restaurant. A friend follows her out, and returns some time later, alone.

I drive home later that evening with a sound-worm digging into my brain. It's a B52s song. The simple melody and lyrics play over and over. I'm aware of how flippant the words are, but they won't leave me.

*You're living in your own private Idaho, your own private Idaho.*

I hope she'll be able to get out of that state soon.

The co-ordinator of our respite service phones me to tell me that she is retiring and will finish up in the next two weeks. I thank her for her recent support: she helped Millie and I retain Janie, our lovely carer whom we have known for many years, when administrative changes at her organisation threatened to cause us problems.

Then she says to me, I want to let you know that I admire you.

I'm taken aback. Whatever for? I ask.

You seem to have a life of your own, she replies.

I'm pushing a loaded trolley as it veers and swerves across the tarmac. My arm is entwined in Millie's, to keep her, too, on track. Just in front of us, a man in a wheelchair heads for his car which is parked in an accessible parking spot near ours. He packs his shopping bags into the boot, then he comes over to us, just as I am loading Millie and the groceries into our car. I know this man: he is a disability activist, and I've come into contact with him several times through projects I've worked on. But he doesn't appear to recognise me. He says, Do you know what disabled car spaces are for?

I've got some ideas, I say.

Well, he says, for people like me, they give us a wider space so we can get in and out of cars with a wheelchair. For people like your daughter and you, you just get free parking all day.

Whatever could he mean?

## ***A philosophical question***

There in that fluorescent room, in that big steel-framed bed, fastened to countless tubes, hooked up to bags of fluid and blood, she looks so very vulnerable. Her skin is ashen, her cheeks swollen, her lips slack and distended from lying face-down for way too long. Her eyes flutter and struggle to open; there's fear in them, and too many questions about the mystery of who she was yesterday and where that girl has gone today.

She drifts in and out of consciousness, she catches fragments of the present, with its heavy footsteps and shrill voices, and hands that poke at her, and buzzers and bells and bustle that fill the air around her and then disappear as she is pulled back into the hollow morphine dark.

I sit beside her, and hold her small limp hand. I touch her, and feel her coldish flesh. I watch her, and watch out for her. All the while my heart is breaking.

They brought her down from intensive care this morning. She had been there for twenty-four hours following the operation. Now that she is here in this room I can breathe a little easier. Somewhere deep inside me I know that she is going to be all right. Maybe not right now, but sometime soon.

While I stroke her fingers and sing softly to her, I can't help going over the same painful thought, again and again. It clutches at my stomach, and catches in my throat. We did this to her; we made this choice for her; we don't know yet if it was the right one.

On a hot sunny day last November, I took Gabrielle and Amelia to our favourite local swimming pool in a park surrounded by bush. We put our gear on the grass, and I peeled off Amelia's T-shirt and shorts and slathered her with sunscreen. Then she wandered off towards the pool in her bikini, to join her sister in the pool. I dashed after her. But then I stopped. Something was wrong. Amelia's spine, that had always been so straight and strong, was somehow turning in on itself, collapsing, or maybe just giving up in its effort to hold her body upright. What had been vertical now was twisted into a loose S shape.

In winter and early spring you make a rapid transit between bath and pyjamas, you dress in a hurry, and your body gets lost in layers. It's only in warm weather that your body sheds its cloaks and shields, and your skin and bones are there on show, with all their gifts and faults exposed. It was eight months or more since I'd seen Amelia's body in long shot; her back and shoulders then sharp as a T-square. But something had happened since last summer.

The next day I contacted the school physiotherapist, who examined and measured and assessed Amelia, and then pronounced: *scoliosis*. The physio said that the condition wasn't unusual in teenagers with disabilities like Amelia's that involve low muscle tone: with the growth spurt of adolescence, the spine is not able to maintain its position without the support of the strong back muscles that typical young people have.

At that time when Amelia was in her final year at school, Gabrielle had just started high school and Laura was at university. Peter and I had been living apart for two years. Our marriage that had withstood so much crumpled under the accumulated strains. We were always the couple that were going to make it, but cracks had formed. Over the years they grew wider and deeper. I rented a house in a town a little further down the Mountains, and we shared the care of our daughters. It was a difficult time, financially and emotionally. My mind constantly played over the impact of this separation on our girls.

With Amelia's scoliosis to deal with, we knew that we would have to work together. I took Amelia to her GP, and we discussed various treatment options, including bracing (long term, highly uncomfortable and of limited benefit) and surgical remediation. This involved a major operation that was extremely delicate, with a significant level of risk. Peter and I took Amelia to see the leading orthopaedic surgeon in this area at the Children's Hospital. We had been warned: while his technical skills were impeccable, his poor communication skills were notorious. In the consultation room, his registrars buzzed around and did all the interpersonal work: they welcomed us, made jokes, and interpreted his commentary for us. Meanwhile, he examined Amelia, and assessed the degree of her scoliosis (at over forty per cent, it was considerable).

There is a strong likelihood that this abnormality will worsen over the next few years, he said. Spinal fusion surgery is a possible treatment intervention; it is best done before the age of twenty-five, while the patient's bones are still malleable. During this procedure, steel rods are inserted into the patient's vertebrae (in this case, in the thoracic and lumbar regions) in an operation that takes six to seven hours. The patient spends ten days in hospital, followed by a convalescence period of around ten weeks. During this time, the patient must rest, may not attend school, and must avoid crowds (where she might be knocked and hustled about).

While this operation does not cure the abnormality, he said, it will improve posture and may prevent further deterioration. Over time, the steel rods fuse with the vertebrae to provide structure and support. Do you have any questions?

We had to concentrate hard to take in all this information.

What is the risk of complications in this surgery? we asked.

There is a five per cent risk of neurological damage to the spinal column, he answered. Then he told us that he had never had any adverse outcomes in his patients. He often performed this surgery on 'those ones', he said, nodding towards Amelia; 'the walkers', like her, tended to do better than those in wheelchairs.

What is your recommendation? we asked. Is this operation the best option for her?

His eyes, sharp and grey beneath the domed forehead, shifted upwards to meet ours. Well, he said, that's a philosophical question.

Peter and I exchanged puzzled looks. Is it? I asked.

The doctor shrugged. The decision is yours, he said.

In the car on the way back to our separate homes we wondered about the surgeon's cryptic response, that this was a philosophical question. More pressing, however, was the dilemma that we faced: on the one hand, if we went ahead with the operation, we would be exposing Amelia to something risky and traumatic. On the other hand, if we chose not to proceed, we faced the possibility that Amelia's condition would worsen. I knew of one family from Amelia's school who had chosen not to have the operation, and their son's spinal problem had deteriorated so that his lung function was now seriously affected by lack of space in the thoracic cavity.

We needed to get further advice, and there was really only one person who could help us, whom we could trust to speak in Amelia's best interests: her paediatrician from years ago, the one we had taken her to when we first moved to the Mountains. The one who had helped us get Amelia into the school where she blossomed. The one who didn't mind when I called him up from time to time in desperation. The one whom parents of Mountains kids like Amelia referred to as The Saint. Some years ago he had moved far away, but we could track him down. He would know what was best for our daughter.

When we found him and took Amelia to see him, philosophy didn't rate a mention; his focus was on balancing benefit and risk. He examined Amelia, computed the degree of her scoliosis and, using some kind of formula, he calculated the extent of possible future impairment. To these objective measures he added a large dose of empathy. He said things like, 'If Amelia was my daughter ...', and, 'What we've got to think about is Amelia's future and her quality of life.' He thought for a while. Yes, he said, after the examining and testing and evaluating, this surgery is the best option for Amelia.

He sent us away with a referral for an MRI of her spine, which was needed for the surgery, and for which she would need a general anaesthetic to keep her still. Since she's having that MRI, he said, we should get one done of her brain at the same time. Years before, he had resisted doing this, because there was no clear benefit for Amelia that would counter what he perceived as the ever-present risk associated with an anaesthetic or any other kind of intervention. Looking inside her brain again was not really going to help her, he had told us then. But now there was the chance to take another good look.

We were pleased that he was involved, that he had helped us with our decision. But I was hesitant about the brain MRI: investigations into the cause of Amelia's disability belonged in the past. Now we just got on and lived with it. The thought of all those questions resurfacing made me anxious, and I didn't need another worry to add to my fears. Lurking beneath the anxiety was my old adversary, guilt: after all these years, I was still terrified that those pictures would reveal some awful truth about Amelia's condition that pointed back to me. This was the shameful, selfish secret that I carried with me as we bundled Amelia out of the car and into yet another hospital in the northern suburbs a couple of weeks later.



It was the most unpleasant hospital we had ever been to. We descended into a labyrinth, a cold wind gusting through concrete tunnels, an endless endoscope through the bowels of the hospital's anatomy. Finally we found the dingy area that was Medical Imaging. We waited, as always, then Amelia was given an anaesthetic and wheeled off somewhere behind heavy grey plastic curtains. We met her in recovery an hour later, and trundled our groggy girl back to the car in a wheelchair. The pictures would be sent direct to the paediatrician.

I didn't want to see those pictures. Maybe I just didn't want to know.

Or maybe I had other ways of knowing my daughter. I loved her, and I understood the person she was. I knew her past and her present: her life story. I knew how to care for her. And as her mother, I knew her through my very body. I thought about Amelia's ways of knowing, too, and how she knew me: through her senses: sight and sound and smell and touch. For her, sight meant recognition, sound meant music, and touch, connection. Her ways of knowing were as complex as anyone else's: they were deep and metaphorical.

The surgeon saw her through the lens of scientific knowledge: she was a pattern of symptoms leading to a diagnosis. He knew her as an abnormality to be remediated, or maybe not. All he could see was her disability. Once we ventured into his world, we had to accept that his kind of knowledge was the valued currency.

In mid-July I was phoned by the hospital and informed that a cancellation had freed up a place on the surgery waiting list: Amelia's operation would take place in three weeks' time. This was a big surprise, as we had been scheduled in for the next January. A couple of days later, Peter took Amelia back to the paediatrician, to follow up on the MRI scans. That evening, he brought Amelia back to my place. The pictures of the spine, he said, confirmed what the doctors already knew, and they provided the details that the surgeon needed for the operation. He took a long breath then before continuing.

It was the brain scans, he said, that delivered the shock. Basically, they indicated that all the past conjectures about Amelia's condition were incorrect. Our daughter had not suffered a third trimester brain injury, nor was she exposed to an intrauterine

infection. Instead, the scans indicated a problem in the earliest stages of brain development. The connective tissue between the hemispheres in Amelia's brain – the corpus callosum – had not formed, and the reduced brain matter was secondary to this.

Peter is upset. He finds the telling too hard. Tears roll down his cheeks. Sobs unleash from within him. He lets go of all that he has been holding back for all those years. He has to abandon what he had understood for so long about his daughter. But he also finds release in this ultimate knowledge. I want to reach out and be there for him but there is a great gulf between us now.

He has the pictures with him, in a large envelope. He asks me if I want to see them. I shake my head. He says I should look at them, but my breathing becomes shallow and I begin to sweat. These pictures are triggers, reminders that take me back through all those years. I have to calm myself. I tell myself it doesn't matter, whatever they say. I hold on to the different kinds of knowledge I have of my daughter.

When we are calmer, we talk about how years ago, our paediatrician had accepted the reports of the first specialists who had seen Amelia. But when it came down to it, those reports were based on beliefs, not evidence. The knowledge that those doctors were trading in was not the truth. They presented to us facts that were really no more than hypotheses. And out of those assumptions emerged our own ideas and fantasies and fears about Amelia. Now it was time to lay them all to rest. But in the end, this new knowledge didn't change anything for Amelia. There was nothing that could have been done for her that had not been done.

She is who she is and always was, in spite of all those reports and these pictures.

In late July, we went back to the clinic for a check-up before the operation. The surgeon spoke to us briefly, then motioned his registrars to follow him into an adjoining room. The door was open just far enough for us to watch as he sat in front of one of the computers lined up along a benchtop, and brought up the MRI scans of Amelia's spine on the screen. The registrars gathered around and nodded as he spoke and pointed. He closed the files, and the others were just turning to leave the room when he said, Wait a minute; come back and have a look at these.

They gathered around again and bent their heads towards the screen. There were different images up there now. We could hear words like ‘abnormality’, and we knew they were examining the scans of Amelia’s brain. We felt very strongly the violation of our daughter’s privacy: those registrars didn’t need to see those scans; they did not need to have that knowledge.

Two weeks later, I packed Amelia’s bag and Peter picked us up very early to avoid the peak hour traffic on the western freeway.

We were nervous about the operation, and we agonised because Amelia had no idea of what was about to happen to her. I sang to her our hospital song, and showed her the packed-up bag, and talked about doctors. But essentially, we were leading her into the unknown, removing her from her happy, predictable world. And she had no say in it. As we walked up from the hospital car park, she was smiling, clutching Peter’s hand and happy to be out with both her parents, who were together for the day.

We sang to her while we waited in the surgical ward, and gave her slippery red jelly that landed on her clothes and in her hair, as well as in her mouth. Then we dressed her in a backless hospital gown, and accompanied her as she was trundled through into the holding room. We stroked her while she was jabbed with a pre-med. When she was called by the doctors, I went with her into the operating theatre and sang *Waltzing Matilda* close to her ear. I cried as she fought the gas mask that was held firm over her nose and mouth, before she finally drifted into the oblivion of anaesthesia.

During those seven hours we paced the hospital corridors, and went out for lunch, then came back again and tried to read books and newspapers. Then we paced again. It was dark outside when they finally buzzed us to say the operation was over and our daughter was recovering in intensive care. She lay there, a small wounded creature in that dimly lit room, surrounded by gleaming steel and flashing lights and neon monitors. A doctor hovered over her, and told us the operation had gone well, but she needed constant surveillance. As she began to stir, she tossed and whimpered. We felt her discomfort and confusion as if it were our own. She became so distressed that she began to thrash about and tear at the tubes and wires attached to her hands and wrists.

The nurses came in and bound up her hands to the bed rails with Elastoplast so she wouldn't dislodge them.

A monitor beeps now, a red light flashes. The drip needs changing. I wait for a nurse. I can just see them from here, four of them, hovering around their station. *Why don't they come?* The sound shrills on and on.

I'm getting anxious now. I have to fetch a nurse.

I poke my head around the doorway, and catch their attention. One of them enters the room, and fiddles with the apparatus. It's also time to top up the morphine, she says, and check blood pressure, temperature and pulse. My daughter is sleeping, her eyelids are fluttering and her breathing is scarcely perceptible. I recoil as the nurse hefts her out of her slumber and into the glare. Amelia yawns and grimaces and fights her way into consciousness.

I'm here, I say, and stroke her pale arm.

When the nurse is finally gone, and I am helping her back into sleep, I promise in a whisper that someone who loves her will always be there for her, someone who knows how to care for her.

We have booked a room at the parents' hostel, and we take turns to stay overnight. We carry a bleeper with us at all times. We buy rolls for lunch and eat them at Amelia's bedside. We chat with the parents of other children in the ward. We live and breathe the ecosystem of the hospital.

Amelia's aunt Bibi comes often, as well as her grandmother and her godmother. Her sisters help to bathe her and read stories to her. Teachers from her school come to visit and bring cards made by their students. We make her room bright with pictures and flowers and soft toys. We set up a music station on her bedside table. There is a lot of love surrounding her.

But it takes many days before we see signs of the girl we knew returning to us.

On the tenth and final day in the hospital, I wash Amelia's hair in a basin and dress her in fresh clothes. A troupe of doctors and the nurse specialist enter the room; they

pull curtains around her bed and set about examining her. They remove her bandages, and we see for the first time her back: a thick red scar, raw but dead straight, criss-crossed by black stitches, running from between her shoulder blades down to her coccyx. Amelia squirms in discomfort as the nurses change the dressings. They give us letters for her GP and prescriptions for Endone to collect at the hospital dispensary. They give us a folder of instructions on postoperative care: on managing Amelia's body and her wound and on weaning her off the pain medication. They give us the number of the nurse specialist to call if we need to. They tell us when we must come back for follow-up. They organise a wheelchair for us to take home.

Peter goes to fetch the car and I wheel our daughter out into the street. As we load her carefully into the car, we feel as helpless and anxious as we did when we brought our first newborn baby home from hospital all those years ago.

Ten weeks is a long time for a recovery. It's a long time for a girl to be unable to move much, and then gradually, painfully, to start getting around; to be away from the school she loves; to be trundled between two homes and two parents; to be cajoled into eating and drinking when she doesn't want to; and to have large quantities of PainStop forced down her throat because she may no longer take the small powerful doses of addictive Endone.

Ten weeks is a long time for parents to manage round-the-clock care, and juggle work and the needs of other children. As luck would have it, Peter is between jobs, so he has time available for the first half of that period. Not so for me: I have a program of training sessions to deliver that has been planned for months.

The first weeks are difficult. Dramas small and large play out around us, support acts to the main feature that is Amelia's recovery and the huge responsibility that we bear in caring for her and bringing her back into the world she knows.

A week after Amelia's return home, I take her to our GP for a check-up. He doesn't know whether he has to remove the stitches or not. He tells me to call the nurse specialist at the hospital. She tells me that the stitches will absorb, that the doctor should know this. The following week, I have to go back so he can check that the wound is clear of infection. Because we always have to wait a long time, I ask the receptionist to phone me beforehand, to let me know when we should come up to the

surgery. She does, and when we get there the waiting room is full of mothers with toddlers, and older people camped in chairs around the walls. Their eyes, wide with pity, all fix on the pale girl huddled in the wheelchair. After a while, the woman behind the desk – the practice manager – calls me over.

Doctor is unable to see Amelia now, she says.

But I rang not long ago, I say. You could have told me then.

Doctor has to go out. He will be back in an hour, and you can see him then.

I try to explain that we can't wait: Amelia can't stay upright in the wheelchair that long, her medication will be well overdue, and I'm not able to get her home and back in that time. Can I get an appointment later this afternoon, or maybe tomorrow morning?

He is fully booked, she says.

The other patients exchange disgruntled looks. One of them, an older woman says, It's my turn next, with the other doctor on duty; I would like this girl to take my appointment.

A hubbub is brewing: half a dozen others are willing to offer their slots to us. But the woman behind the desk hushes them. No, she says, and turns to me. That other doctor cannot see you. If you can't stay now, I will make an appointment for you next week.

I thank the roomful of supporters. I grip the handles of the wheelchair hard as I push Amelia back to the car, holding back my tears. Our GP is there in the car park, fiddling with his keys. I tell him I can't believe what has happened. He says he has a case meeting to get to; the receptionist made a mistake by confirming the appointment over the telephone.

I say, That isn't good enough; I made that appointment a week ago and my sick daughter needs to see a doctor today.

If you don't like it, he says curtly, you can always go somewhere else.

This man has been our family doctor for twelve years. But it's clear he doesn't understand Amelia's needs at all.

I take my daughter to the walk-in clinic at another GP practice the next morning. We arrive early, so we don't have to wait too long. The doctor there removes the bandages and examines the thick scar that courses its way down Amelia's back. The stitches have just about dissolved. But the wound is honeycombing, the doctor says. Good thing you brought her in. She needs more antibiotics. He calls in the practice nurse, who gently re-dresses the wound.

But it's not only Amelia who needs intensive support. A few days later, Gabrielle arrives back from her jazz ballet class, carried to the door by the friend's father who was driving her home. She has dislocated her kneecap while dancing, and she is in agony. I dose her up with Amelia's painkillers. Next morning I race her to the same new doctor – in Amelia's wheelchair. She is bandaged up and referred to an orthopaedic surgeon and a physiotherapist. The physio manipulates and massages and hooks her up to mechanical devices, then commands her to follow a gruelling exercise regime. The orthopod tells us that if she had come down to emergency straight after the injury, she would have gone in for surgery. But, he says, it looks like all the bandaging and bracing and exercise is getting the kneecap back where it should be. Gabrielle won't need an operation. She has 'squinting kneecaps', he says, and the injury was an accident waiting to happen. Her dancing days are over.

So we have two immobilised children requiring special care. Amelia's needs are so high that Gabrielle probably doesn't get the level of sympathy that she may be entitled to, but I do my best. We get help from my sister, and our long-term respite carer, Janie. Amelia's big sister, Laura, helps too, but she is immersed in writing her university honours thesis. Her research, on the rights of people with intellectual disability, will include a beautiful reflective narrative about her relationship with her sister, and this will earn the high praise of her examiners. In it, she writes lyrically about Amelia's operation and recovery, and how the nursing staff often called upon her special knowledge of her sister to help them interpret her wants and needs.

Six weeks after the operation, we take Amelia back to the hospital clinic for a check-up; her recovery is unfolding as it should. Things change on the care front when Peter's new job starts at the beginning of October, but by then Gabrielle is getting about on crutches, and she is back at school.

Amelia's recovery period of ten weeks stretches to twelve because the last two weeks coincide with the school holidays. She is stronger now, and can walk about in short bursts. She has regained a surprising amount of movement in her body, but when she bends over, the movement comes from her hips; her back remains horizontal rather than curved, held together with the rods and screws that have already begun to fuse to her spine. When she stands now, she is straight and tall again.

On that first morning when the school bus pulls up out the front of my house, Amelia greets Bert, her driver, with delight. She is ready to resume her life, and this will be her final term at school. I strap her carefully into the front seat, in her special place next to Bert, and heft the wheelchair into the back. Her bag contains letters to her teachers and therapists about what she can and can't do, and how to manage her movement and transfers. I stand at the gate and watch the bus disappear around the corner: it's so hard to let her go.

That evening, Peter drops in on his way home from work to see how Amelia's first day has gone. She is smiling, and we smile too to see her face once again painted with joy. The note in her bag from her teacher confirms that she has had a happy day.

We sit outside in the cool October evening with cups of tea, and talk about where those past three months have taken us. We know now that we made the right decision for Amelia. Surgery was definitely the best option for her.

We talk about how there were other forms of healing taking place in those hospital rooms as well. How when we swapped shifts, we drank coffee together at Amelia's bedside, and when we collected our various belongings from the parent room, we talked for the first time in months. How we alone knew what the other was going through. How we had to work together as a team. How the gates began to creak open all those months ago when we first entered this ordeal.

In just over six months, we will be back together again.

We talk about the doctors, and especially the surgeon whose skill and knowledge have granted Amelia a better future. We're grateful, of course, but we also ponder the way he related to us and to Amelia, how she seemed to be for him no more than a configuration of faulty anatomical features to be corrected. How we needed his knowledge, but our other ways of knowing her were irrelevant to him.



It's dark now, and we can hear Amelia inside, singing along, in her way, to the music on her CD player. A gust of cold air suddenly whisks around us, and a shiver runs through me. We come back to the surgeon's comment, that the decision about Amelia's surgery was a philosophical question. I hesitate, because I'm not sure I want to give voice to my uneasy thoughts. Because his question is more deeply concerning than we were prepared to acknowledge back then. His question sprang from the site where issues of morality and medicine come together, and for people with intellectual disability, that has never been a comfortable place. The surgeon's philosophical question was actually a bioethical one: about whether a complex procedure like spinal fusion surgery, which mobilises considerable economic and human resources, is justified in the case of someone with severe disabilities, someone like Amelia. I don't say these words, but when I turn to look into Peter's face, I'm sure he understands this already.

Yes, it is justified. And yes, she is worth it.



## ***Graduation***

The hall is crowded with mothers and fathers and children and grandparents, many standing at the back because all the seats are taken. We get to sit right at the front this year, Peter and Laura and Gabrielle and Grandy and Aunt Bibi and I. We sit patiently through the Principal's short speech, all the class awards, the therapy awards, and the special presentations. The students wait together in the room behind the stage until their names are called. Then the teachers help them, one by one, on to the stage where they receive their certificates to their claps and cheers of the audience.

It's time for the Higher School Certificate award: Amelia's big moment. To make the presentation, they've invited the woman who was principal of the reverse integration preschool where Amelia went there all those years ago. We're surprised by this, but no-one here knows the full story of that chapter in our history, and we're not going to let it concern us now. The preschool ex-principal says some nice words about Millie, about when she was so very small, and how far she has come.

I see Amelia standing at the edge of the stage, accompanied by one of her teachers. She stands tall and her face is shining. She laughs as she makes her way towards the podium with her escort. Her neatly brushed hair gleams under the bright lights. I am so proud of her. Every set of eyes in the audience follows her as she steps forward and the old principal places the gold trophy into her hands. She moves a few steps back and looks out over all those heads and faces with her deep blue eyes so fine and clear. Tears roll down my cheeks as I hear the applause of the crowd, their claps all for her, my daughter.

Then a big screen appears on the stage, lowered from the roof, and the hall grows dimmer as a DVD begins to play. It's all about Amelia, pictures of her spliced together with music, from baby to preschooler to classmate to school-leaver, looking and laughing and sometimes crying, with family and teachers and friends, at the pool and at the zoo, bushwalking and sailing and gardening, eating and reading, carrying her shopping basket and riding her trike. Seventeen years of her life cut and pasted into a colourful ten-minute kaleidoscope. Everyone in the crowd is oohing and

aahing, and we can't believe how wonderful this is. In other years, the annual DVD has included all the graduating students; but because Amelia is the only one this year, this movie is all about her.

When it's finished, we take Amelia back to her classroom where we join with the other students, their parents, the teachers and the volunteers for a Christmas party. Just three days more, and school will be over forever.

After ten years at this school, it was hard to think of moving on, of leaving behind the friends and the teachers, all the familiar faces and places, and venturing into the unknown. It was as if the safety net was being pulled away, and we were in free fall.

Preparations had been unfolding for many months. In May, Amelia commenced the School Leaving Process, and the paperwork began to pile up. Unlike her older sister, Amelia didn't need to complete assignments or sit formal exams. She didn't have to study hard or worry about getting into the course of her dreams.

The following January she will receive a big package by mail that contains her Higher School Certificate portfolio, just like all other school-leavers. She will be awarded passes (but no marks) in these subjects:

*2 Unit English Life Skills*

*2 Unit PDHPE Life Skills*

*2 Unit Citizenship & Society Life Skills*

*2 Unit Science Life Skills*

*2 Unit Creative Arts Life Skills*

*2 Unit Technology & Applied Studies Life Skills.*

But these results won't be linked to her academic performance. She was spared the stress-fest that her sister went through, but that doesn't mean she wasn't examined.

The first stage involved an eligibility assessment for a post-school program. The two available options for school-leavers like Amelia are Transition to Work or Community Participation. Amelia would go straight into Community Participation because future employment was not an option for her. She would attend a centre-based program, in which she would participate in a variety of activities designed to

develop her life skills and provide opportunities for social interaction. This was the easy part.

The hard part came next. How much support she would receive, and how many days per week she would be funded for, depended on her results in this assessment. She would be ranked in one of four funding bands: low, high, very high, and exceptional. If she received a 'low' or 'high' result, she would be entitled to three days' program funding. On the other hand, if she came out with a 'very high' or 'exceptional' ranking, she would be granted funding for a five-day program with a higher level of staff support. So the students who gained 'low' grades were actually those with the most ability. Conversely, the 'exceptional' grades went to the most disabled students: those who needed a lot of help with all their daily activities.

There was a painful irony in this. I couldn't help comparing Amelia's assessment process with that of her sister. Laura fretted over which of the six performance bands her HSC marks for each subject would land her in. For her, a better performance ensured a higher band. For Amelia, the reverse was the case.

The school sent out consent papers and scheduled a meeting to conduct the assessment. On a chilly afternoon in June, I sat down with Amelia, her classroom teacher, and the school psychologist to complete the forms. During the meeting, her speech therapist, occupational therapist and physiotherapist were invited in separately to provide their input. The 'screening tool' that the psychologist filled in during the meeting consisted of a battery of multiple choice questions, in the manner of so many exam papers. But all these items were about Amelia's skills in daily living and self-care, and her behaviour, and we answered them all on her behalf.

It was a curious assessment: while we were proud of Amelia's achievements during the past ten years, we had to be mindful of our goals for her. I had to keep reminding myself ruefully that the worse she did, the better the outcome in terms of resources for her future. After the papers were submitted we had to wait until September for Amelia's results.

The next stage in the process involved finding the best post-school program for her. I obtained a list of service providers in our area, and spoke with teachers and other parents who had been through the system. The post-school program that her teachers recommended was forty kilometres from home, much too far away to be

feasible. No one from the school really knew much about what was happening around the Mountains. I trawled through websites and attended disability expos. I visited centres up to twenty-five kilometres away from our home, in the direction towards the city, closer to my workplace.

Suddenly these investigations had to be put on hold: Amelia's spinal fusion surgery was brought forward from next January to August, just two weeks away. For the next three months, we were submerged in the world of hospitals and post-operative care and rehabilitation. It was almost impossible to find the energy and mental clarity to sort through all the post-school information, and make critical decisions about our daughter's future, while we were so worried about her and caring for her so intensively.

Not long after her operation, her assessment results arrived: she had achieved a 'very high' ranking. We were pleased and relieved because she qualified for a five-day placement.

When Amelia returned to school in October I resumed the search. With only two months to go before the end of the term, the pressure was mounting. The first Community Participation program I saw was based in a house in a suburb near the university. I went there first because I had met the co-ordinator when I was working for a disability research organisation, and she had impressed me. But this tumbledown house, with its shabbiness and its odour of stale food and urine, soon became for me an emblem of this post-school disability world. There was a sense – in spite of the good intentions of service providers and their staff – that this was the best we could expect. The rationale was that programs should be sited in the community, in 'normal' homes, part of everyday life. But this home, and many others like it, were not normal: they exuded poverty and otherness.

I heard about another program closer to home that would be opening in the New Year. Progress had stalled, apparently, due to planning issues. I drove past: it was a much newer and tidier property, and I felt a spark of confidence. A couple of weeks later, though, someone from that organisation phoned me to say their application had been rejected by Council. Then someone else told me that services for people with disabilities were prohibited in residential areas in this LGA. I found this very

surprising because, in the heartland of Western Sydney, that LGA is not known for its exclusive neighbourhoods.

A couple of other options surfaced, all sited well away from 'normal' residential homes. One program was located in an industrial unit across the road from a cemetery. It was dark and dank, and in the small concrete courtyard at the back there were industrial-sized tubs of Ratsak. Peter came with me, and shook his head in despair. The co-ordinator was delightful, however, and did her best to reassure us that the 'guys' really didn't spend much time there anyway, as they were mostly out and about in the community. The next place was beautifully situated on the banks of the Nepean River; but it was a huge tin boatshed, with boats in racks and navy memorabilia along the walls, and a couple of makeshift rooms done out with tatty second-hand lounges. I could only imagine how the wind would whisk through those unclad iron walls in winter. The final option was a shopfront in the middle of the business district. Amelia's school teacher kindly offered to accompany Amelia and I on this visit, to give his opinion of how it would meet her needs. It was neat and clean, but when we arrived for our appointment, the staff left us waiting for almost an hour without even acknowledging us. The teacher couldn't stay any longer, but said he would come back another time. I began to accept that this was our last resort, until the teacher contacted me to say he had been back, and had had a similarly unwelcoming experience; he was worried, too, that there was no outdoor area for Amelia, who loved to be outside in the sunshine.

Time was running out. In desperation, I phoned the program that the school had recommended, that was so far away, but they were full. Up till now I had resisted considering programs that were in the Mountains, because I was trying to juggle my needs with Amelia's, and find something that would be compatible with a working life for me. But I could no longer make such a compromise, and risk a placement in which she would not be happy.

There were two possibilities in the Mountains. The closest – three kilometres from our home – was a former guide hall in the middle of the bush. It reminded me of the tin boatshed, but instead of on the riverbank, this structure sat on a pile of gravelly rocks. I could just imagine Amelia walking outside and tripping over the sharp stones. The other was much further west, up the Mountains, too far away, too difficult for the family. Until now.

This program was housed in a charming turn-of-the-century timber home with a wide verandah and a small but well-tended garden. It had been donated by the local council for the use of the program. The rooms were freshly painted, sunny and cosy. As soon as Peter and I entered, we knew this was the place for Amelia. Her teacher visited the following week, and also gave the thumbs up. With just a week left until the end of the school year, we finally found the right place for our daughter's next stage in life.

It's the big night, a celebration with Amelia at its centre, on par in excitement with her sixteenth birthday eighteen months ago, and her joyful twenty-first party that will take place a few years later.

The school usually does a formal dinner for graduating students and their families. Last year there were six graduands, but this year, there is just one. Amelia's teacher Paul suggested that a poolside barbecue in the school grounds would be more appropriate for this girl: she wouldn't have to sit still, and could walk about among her friends. He asked me to put together a guest list. The number of invitations kept growing because so many of Amelia's therapists and teachers and aides and respite carers and volunteers wanted to be there, as well as our family, godparents, friends and a couple of other school families.

On the morning of the event, it's raining hard, so the venue has to be changed to an indoor dining room. But that's the only glitch. After school, Amelia goes over to the respite centre, so that she doesn't have to come all the way home and then return later. There, Judy, her favourite respite person, bathes and pampers her. I arrive soon after with her sisters and her new clothes: she has a lovely new peach-coloured dress to wear, new shoes, and some frangipani flowers for her hair. She looks beautiful. Later her father comes in, straight from work, and he gasps when he sees her. Then Bert, Amelia's bus driver, and his wife and son and daughter appear; his family have foregone their own son's school presentation evening to be here tonight. We feel very honoured and humbled by their gesture.

The dining room fills with people, all talking, and taking photos, and exclaiming over Amelia. We eat and drink, and the speeches come, all the tributes and thank yous and celebratory words. It's bittersweet for us, this time of remembering and



saying good-bye. Paul reads a poem written by Jenny, a volunteer in Amelia's class. It's called 'Millie', and includes these words:

*A beautiful mystery  
deep in your soul  
reflects a spirit  
shining and whole...*

*Keep singing Millie.  
The world needs your song.*

There's not a dry eye in the room. Then I read a letter that's my attempt to put into words what Amelia might wish to say to all these people who love her:

*To my friends at Alice Betteridge School*

*I can't tell you these things myself, so I have whispered them to my mother in our special way, and I have asked her to read this letter out to you tonight.*

*When I came to Alice Betteridge School nearly 11 years ago, I knew it was the place for me. People were happy. They smiled at me and made me feel welcome.*

*I was a tiny girl then, and the world and its people were a mystery to me. Bit by bit, my friends here have helped me put the pieces of this puzzle together. Over the years, you have shown me what I could do and who I could be. You have been patient with me, and you've waited, sometimes for a long time, for me to be ready to go ahead. You've shown me how to express myself, and you've respected me when I have. You've helped me to find my place in this big world. Most of all, you have believed in me. Thank you so much.*

*I've had many teachers since those first days. I will treasure memories of all of you. For the past three years, I've been with the wonderful people in Classroom 13. Paul is an amazing teacher and a precious friend. Paul, you and all my friends from Classroom 13 will be in my heart forever.*

*Now that I'm leaving ABS, I'm feeling nervous. I don't want to leave you, but I'm not that tiny girl any more, and I need to move on. There'll be new mysteries*

*ahead to solve and more puzzle pieces to put together. I'm not sure that I'll ever find another place to belong to quite like ABS. If I do, I will be one lucky person.*

*I will miss you all so much.*

*Lots of love from*

*Millie*

But I'm just her proxy; Amelia has always been able to say things so much better, and without the clumsiness of words.

## ***Der Traum***

In Vienna the past weighs heavy on the present. Old stone buildings squat solemn on the city streets, and brood over tombs and statues. Palace walls, staunch with age, guard long-kept secrets within their gilded halls. Close to our hotel a *Flakturm* hunkers down; it will be there forever.

Today, through our window we see the late summer sun shoot wands of morning light across the masonry, and the tree-lined street below is green and shimmering. It is the first time in years that we have spent more than a weekend alone together, and this day is laid out before us like a feast. But last night's dream hangs over me; I try to shake it off, but it clings with cold moist fingers.

'Who could be upset on a day like this?' my husband asks. I tell him that I've had a dream, a very bad dream, too bad to recount. He says I must tell him, he insists, and so I do.

*I enter a house. It's a familiar place, but I step tentatively, because I am an intruder. Slowly I open the door into the living room. The occupants turn to see me, and their faces register shock and distress. They gather around and press against me, preventing me moving further inside.*

*I recognise these people; they are characters from my childhood and adolescence: a schoolfriend, her younger sister, and their mother. They come from England, and the mother, a doctor, is different, more worldly, than the other mothers around our way. Curiously, these people are no older than they were back then, while I am my current age.*

*I have to get further inside that house. I know that my daughter is inside and I have to claim her. I tell these people that I have to see my daughter.*

*But the doctor-mother tells me I cannot see her. 'Your daughter doesn't want to see you,' she says with her long British vowels. 'It's not good for her to see you.' Then she tells me in a voice flat with authority that I need to accept that my daughter is no longer mine, that she belongs with them now.*

*A door opens off the living area and I can see through into another, darker room. I can see my daughter, or the child my dream-self knows to be my daughter, in that room, propped up on a chair and wrapped in a blanket. She is small, about ten years old, not 21, as she should be now. Her pale, serious face is surrounded by a fluff of fine blonde hair. She looks too small, I think. Her wide eyes look steadily out from the darkness.*

*Emotion floods through me: panic, or frustration, or love, I can't tell which. I push past the sisters and the doctor-mother. I go to my child, and extend my hand to touch her. But I recoil: she looks back at me with indifference. It's not that she doesn't recognise me; it's that she doesn't care. The sisters and the doctor-mother gather around her protectively, shielding her from me.*

*'You should go,' the doctor-mother says.*

*'No,' I say. 'She is my daughter and I want her. I want to take her with me.'*

*'You can't do that,' the doctor-mother says. 'She isn't yours anymore. Remember?'*

*But I don't remember. My dream-self searches back through my memory, but nothing materialises to explain all this. There are just brief glimpses, traces that sweep past me and fade into shadows. Truth laps at my ankles, and drains away.*

*'She belongs here with us now,' the doctor-mother says.*

*They turn away. Now I am alone with my daughter. Love and longing percolate through me, pushing me through the shadows towards her. I reach down for her, and lift her, and tuck the blanket in around her small naked body to keep her warm. Then I dash out of that room, and the next, and out of the house with my child-bundle pressed close to my chest.*

*I run out onto the street. They are following me, but I cannot find my car. Where is my car? Why isn't it here where I parked it? I keep running down the road, farther and farther. I hear the doctor-mother shouting behind me.*

*'You can't have her! She belongs here now,' she cries 'We will tell your story. We will tell all about you. Everyone will know what you have done.'*

*Then a familiar paralysis creeps over me. It's an old fear that cuts to my depths and crumbles my certainties. I have done nothing, I am sure, but this is something*

*more powerful than truth. I stumble and fall, the weight of my child suddenly heavy in my arms.*

*I try to move, but I am welded to the road, the doctor-mother's words still stinging my ears ...*

When I am finished with the telling, my husband puts his arms around me on the big Viennese bed. A shaft of sunlight falls across the bright white sheets. 'Don't worry,' he whispers. 'You are a good mother. *Du bist eine gute Mutter.*'



## ***On stealing stories: a letter to the TV journalist***<sup>4</sup>

‘now she walked blossoming above her blood,  
and murmuring, her blood ran deep beneath her’

Rainer Maria Rilke<sup>5</sup>

Dear L., I’m writing to you now because I need to tell you how I feel about the way you stole our story. You came into the foreign territory of our lives with your travel pack and your pocket guide, then you grabbed your spoils and left. You took something with you that was not yours to take: a story, which flared up, bright and brief, and faded away as so many news items do. That was our story. It may have slipped your mind now, but I can’t forget.

Let me remind you.

On a Thursday in March 2013 I caught a train into the city where I registered in the lobby of a tall building and caught a lift up into the sky. It was the day of the hearing, a foreign world of summonses and testimonies, of sessions and tape recorders and *Hansard*. Not long before, I had emailed a submission to the committee, I scuffled it together just hours before the deadline, and then the people from the Senate asked me to come in.

It was the Hearing of the Senate Inquiry into the Involuntary and Coerced Sterilisation of People with Disabilities.

I wrote about my 23-year-old daughter who has an intellectual disability, how she deserves the same rights and respect as her sisters, and that means letting her body function as nature intended. How her coming of age was an occasion for celebration, not despair. How there is no justification for fixing her up so her body will not offend, nor for rendering her infertile so that violations of her will have no visible consequences. How, as her mother and her carer, my work is not only to tell the story of her rights and personhood, but to guard that story and keep it safe.

I had not known that I would be the only parent to write in who did not want to get their daughter sterilised. I had not realised that this story of ours was so badly needed.

Sterilisation was a relic of the dark past, I thought, of the eugenics movement, when ‘ugly laws’ were passed to restrict the access of unsightly people to public places, when those with disabilities were locked away in ‘homes for incurables’, when proposals were put forward to fine parents who produced imperfect children. But I was wrong. And it came as a shock, because I didn’t think the parents of young women with disabilities whom I knew were fighting for the right to get their daughters sterilised.

On that day, in that session, a small group of people gathered in the room, drinking tea and coffee as the senators prepared. You must have been there, maybe somewhere in the shadows, but I did not see you.

While we waited a young man in a suit said to me, ‘You look very nervous, it’s hard to speak in public when you’re not used to it, isn’t it’. Ah, I thought: here I am, the mother of a daughter with a disability, all other parts of me collapsed into the narrow confines of that private identity. Not a writer, nor a speaker, nor a researcher, nor a teacher, nor any other part of me that may once have claimed a voice.

We sat behind a line of desks that faced the senators: the chair, Greens Senator Rachel Siewert, and Labor Senator Claire Moore. They were neat middle-aged women in jackets with serious, sensible faces. We were introduced to the disembodied voice of Liberal Senator Sue Boyce, on a teleconference line. This parents’ session came at the end of a long day for them, with the previous sessions attended by service providers, rights organisations, medical practitioners, and women with disabilities themselves.

One by one, we told our stories to the senators. I found my voice and briefly said my piece. Then another woman spoke, at length: she wanted the laws relaxed, she said, because it was far too difficult to get her teenage daughter sterilised. That would be in her daughter’s best interests, she said, because her menstruation was difficult to manage. The medical specialist and his wife followed, and they talked about the case of their daughter, who was present in that room; they had organised a hysterectomy for her some years ago. Their daughter did not like having periods, they said, and they knew many people who were worried about their daughters becoming pregnant as a result of sexual abuse. Some had taken their daughters overseas for sterilisation, to countries where the procedure was easier to obtain.



The senators asked us questions, and we answered and argued. I could sense the shifting balance as the senators leant one way and then the other. I could feel them hear me and rally behind me. But an emotional broadside from the other camp could set them reeling. The senators said they enjoyed our session because there was passion and debate in the room.

When the session ended, I felt wrung out. I had a heavy load to balance, of rights, and morality and love. I had to weigh up the value of truth and disclosure against my obligations to protect and keep my vulnerable daughter safe.

On the train home I thought about the reasons why those other parents wanted to get their daughters sterilised, and to me they fell short. In our family, the bodies of women were our default landscape: one male among four females. Each of our daughters had been through the transformation from girl to woman, and if one of them needed extra care and help and protection, then so be it. There didn't seem to be a logical connection between fulfilling this obligation, and interfering with body parts.

I suspected that it was a fringe minority that was making all the noise. But you would never get that sense from the submissions to the Inquiry. If you were an onlooker, it seemed that all parents (bar one) were clamouring to get their daughters seen to under a surgeon's knife.

I'm not a zealot. I acknowledge that there will be circumstances in which a hysterectomy is the best option for a young woman with a disability: a serious medical condition, for example. But it distresses me how the bodies of children with disabilities are medicalised from the moment of diagnosis. Doctors will examine and assess and consider the options for remediation. Families will take their child from doctor to doctor, hospital to hospital, seeking a solution. If the child can't be fixed, it will be sent, like an imperfect doll in a toy factory, along a conveyor belt through another door to a different destination. Hopefully, there its family will love it in spite of its flaws.

Surgeons cut and stitch and fix, and if they can't, they may reject. So when a girl with a disability reaches puberty, an opportunity arises to fix what was deemed unfixable. The surgeon's power is reclaimed. For parents, hope gains breath:

somebody is going to do something. The disability may not be curable, but the problem of the girl-woman's body is.

Several days after the hearing an email came from the committee, relaying your request to speak with me. I called you; you said you wanted to do a news story on the inquiry. You wanted to talk with me because I had spoken out against the sterilisation of young women with disabilities. You asked me if you could interview my daughter and me for your story.

As we spoke, questions skittered across my brain, about the ethics of exposing my daughter to public attention, about agreeing to her appearing on national television when she didn't have the capacity to consent herself. The issue was important enough to come out, I thought, but the story would have to be handled sensitively and her portrayal would have to be respectful. I needed this guarantee.

We had done this once before, two years earlier. Another TV channel had run an evening news item featuring Amelia, her father and me, about a particularly demoralising experience on a Sydney ferry. But the current story was different. It was about Amelia's body and its functions. It was about her womanhood and her personhood. It was about the private world of our family.

I asked you about your proposed news item. Yes, you said, you would present the material sensitively; your story is important, you said, and needs to be heard. I asked you who else would be involved. Just the other families at the session, you said. They'll just be there to say a bit about their views, you said, but the aim is to present the material objectively, and to let the viewers make up their own minds.

In the course of the conversation, you asked me what Amelia's mental age was. I answered in the same way I have responded to this question from many people over the years: Amelia's ability doesn't correspond with a phase of childhood development; her take on the world is all her own, a mixture of her talents and impairments. Then you asked me, tentatively, whether someone who has the mental capacity of a child should have to cope with the bodily functions of a woman. But she is a young woman, I answered, who happens to have an intellectual disability.

I should have heeded the bristle of warning I felt then. A sharper one still came when you asked me, 'But by your position on this, aren't you denying your daughter

the right to be sterilised?’ ‘I don’t understand what you mean,’ I answered. ‘It’s not a right to be subjected to a medical procedure that you don’t need and for which you can’t give your consent.’

All the while, I thought you might have been listening.

You must have read all those submissions. In most of them, the practice of sterilising girls and women with disabilities was condemned outright. Stories emerged from women who had been sterilised without their knowledge when they were girls, under the pretext of other procedures. Others told of encounters with medical practitioners who refused to accept they could be sexually active. Sexual health organisations argued that all people had the right to sexual expression and bodily integrity, and that more education was needed so that these rights were accepted and respected. Disability rights organisations, the most unequivocal, called upon international human rights instruments that identified the practice as a form of torture, and pushed for the criminalisation of parents who took their daughters overseas for hysterectomies.

It must have struck you that in contrast, parents’ submissions were overwhelmingly pro-sterilisation. Parents wrote in about their fears of their daughters becoming pregnant and their own horrors of managing menstruation. They described the processes associated with obtaining an order for sterilisation as arduous and costly. They argued that sterilisation was the simplest and best option. One parent claimed that ‘society, and thus government, should feel entirely justified in sterilising people, male and female, with intellectual disabilities’. Another wrote: ‘I tolerate a monthly period only because I wish to have children. It is absurd to suggest that people who have little capacity to manage menstruation and no capacity to care for children, should nevertheless suffer menstruation.’ But you must know many women, as I do, who will not have children but who nevertheless continue to menstruate, simply because that is what their bodies do.

The battle lines were drawn through those submissions. Several medical practitioners also argued in favour of sterilisation, but it was clear that the chief contenders were the disability advocates and the parents. There was nothing unusual in this: antagonism between parents and advocates is an unfortunate feature of the disability scene in this country, played out in dramas that include schooling and

supported accommodation. On the one hand, advocates disparage parents for their lack of understanding of the disability movement and its history, and for being preoccupied with relieving their own burden of care; and on the other, parents accuse advocates of fighting for the rights of people with disabilities, at the expense of the rights of those who care for them. For people like me with a foot in both camps, the stretch is often precarious.

You got back to me later with plans for a film crew to come to our house. You wanted other family members involved: Amelia's father and her sisters. While they supported the issue completely, they were not so keen to appear on television, and their lives were busy with other commitments. I didn't push them: it had been my decision. So on the day, there was just Amelia and me and Bunsen, our family dog and her steadfast bodyguard.

You came with your cameraman and your sound man, and your visit was not unlike all those visits that have punctuated the passage of our days since Amelia was a baby. You came with questions, but instead of clipboards and assessment forms, there were bright lights and microphones.

Before filming began, we talked about ways of portraying Amelia respectfully: nothing to upset her, nothing too private or too messy. You and the crew were there for four hours, setting up and filming in our living room while Amelia sat next to me on the lounge. The cameraman said, 'I love this job. I get to meet people like you.' I cringed as I chatted about the inquiry, while you nodded your head and appeared to agree. Then we took a walk through the bush at the end of our street with our dog. I sang to Amelia, 'Waltzing Matilda', our walking song, while the camera followed us along the track. Amelia, I thought, had been just perfect. And all the while, I thought you were hearing me.

There's a darker side to this issue that I need to expose you to. You're a tourist in this country, and you've seen some of its topography. But those who excavate this landscape will tell you that a deep vent lies beneath the surface, far below the laments of parents and the surgeon's scalpel and rights rhetoric. It deals with the subterranean

fears that bubble up when we bring together cognitive impairment with the processes of a woman's body: both lurk outside the acceptable boundaries of the social world.

In her book, *Powers of Horror: an Essay on Abjection*<sup>6</sup>, Julia Kristeva explores taboos around the body and its excretions. Control of these emissions, Kristeva writes, is a necessary step in our journey to personhood. She draws on psychoanalysis to explain how the emerging individual in a patriarchal culture like ours must deliver 'the clean and proper body' in order to make the transition from the body-centred realm of the mother to the language-centred symbolic order of the father. She uses the term 'abjection' to describe the status of bodies that fail to make this transition, that remain uncontrolled.

At the centre of abjection is the woman's body, a leaky body. Its closeness to nature and its permeability –the way inside and outside get confused – place it in opposition to the controlled body of the (male) symbolic order. Its offending processes, particularly the blood of menstruation, must be kept invisible. When these processes spill out of the private and into the public sphere, a taboo is transgressed. A sense of horror is unleashed.

Similarly, the disabled body is marginalised; it is not 'normal', and it too, is uncontrolled. Rights theorist Tom Shakespeare has claimed that disabled people are used as 'dustbins for disavowal'. And within the hierarchy of disability, people with intellectual disability are close to the bottom of this trash can. Most typical children will learn to control their bodily functions, to enable progress to the symbolic order. Not so those with severe cognitive impairments: their bodies, and by association their selves, will remain in this state of abjection. The girl or woman with intellectual disability brings together the horror of both the woman's body and the disabled body. She embodies a double abjection.

The release of the Committee's report was delayed until the middle of July. I asked you to ring me to let me know when the story was going to air, then I sent texts and emails to Amelia's friends, family and support workers, who were all excited to be seeing her on television.

Our family gathered around the television. You began with scenes at the home of the woman from my inquiry session: warm family scenes of the teenage daughter

together with her brothers and her parents. The woman spoke about the difficulties of managing her daughter's menstruation, how the sight of blood upset her daughter, how she would never be able to cope with this independently, and how solutions other than sterilisation were not an option for her. She spoke about how difficult it was to obtain permission for a hysterectomy: solicitors and boards and court orders. I could see that viewers would be drawn into the world of this loving family and their dilemma.

When I saw this daughter, I was struck by a disjuncture between the way this young girl appeared on TV and the way she had been described by her mother at the hearing. My impression then was that she must be severely disabled with exceptional care needs, but here was a lively girl who was joining in with her family's activities. She was much less disabled than Amelia; I could only reflect on how relative disability is.

The scene switched to the couple at the inquiry, the medical specialist and his wife, and their daughter, in their comfortable home. The medical man, we were told, was 'eminent'. He informed us gravely of the problems of managing menstruation with hormonal therapy, and both he and his wife said how much better their daughter's quality of life had been since she had a hysterectomy. It was the best thing for her, they said. She no longer had to cope with the indignity of possible accidents in public places, and they didn't have to worry about her becoming pregnant.

It was a well-crafted story. You took viewers by the hand and led them through the dark forest of this issue. The way was well signposted: everyone knew where you were heading. In the safety of their living rooms, viewers could imagine themselves in this predicament, and surely they would respond likewise. They were lucky – they only had to be there for ten minutes or so – then you would guide them back out and they would be safely released.

The screen switched, this time to the talking head of the former Disability Discrimination Commissioner, Graham Innes. He spoke about violations of human rights, about bodily integrity. He was, like the medical specialist father, a male voice of authority in this female underworld. He was put in there for some balance, but by then the hearts of viewers had already been won: love and family never made it into his rhetoric. When he declared that sterilisation was a form of torture, his case was lost. Who could think that after seeing those families?

Then your words, ‘But not all parents ...’ came, and there we were, Amelia and I, walking down our scruffy street with our scruffy old dog and my scruffy voice singing ‘Waltzing Matilda’. I can’t blame you for our scruffiness: that’s who we are. We just didn’t look as squeaky clean as those other nice families; the sun didn’t shine quite the same way through our trees. We were there as the final grab, the obligatory counterargument that wound up the main game. Those four hours collapsed into half a minute, a fraction of the time given to the other families. At least I got a chance to have my sentence heard, about Amelia’s rights, her personhood and her womanhood. But the text messages and phone calls began to come in from friends and family: ‘Whatever was that?’ they asked.

I downloaded the text version of your story; the title was ‘Parents of intellectually disabled girls deny sterilisation breaches human rights ahead of Senate committee report’. The lead went like this: ‘Parents of intellectually disabled girls have spoken out in favour of sterilisation, saying it gives their daughters a better quality of life’.

No wonder you never contacted me afterwards.

Next day, the Inquiry report was released. The recommendations were for strengthening the legal restrictions on sterilisation of people with disabilities who were able to provide consent independently. Forcibly sterilising someone without their full knowledge and consent – if they could give it – should be banned, the report said. But for women like Amelia, who do not have the capacity to consent independently, the same restrictions did not apply. Families could still apply for permission to sterilise their daughters, and they should be entitled to legal aid for doing this. Amongst several safeguards, the report proposed that an advisory committee be established that included non-medical disability, as well as medical, expertise. And it recommended that laws be passed to make it a criminal offence to take someone with a disability overseas to have a sterilisation procedure.

There was a brief flurry of media. Your angle emerged as a novel one. Your radio colleagues, for example, opened with, ‘It may come as a shock to some that people are still being forcibly sterilised in Australia’.

I don’t know how we ended up there, in your news item, whether I was mistaken or misled. Because that story was not mine, nor Amelia’s: it was *your* story.

News items like yours turn the messy business of life, with all its dilemmas and moral complexities, into neat morsels that are easy to digest: more about convenience and flavour than truth. Joan Didion has claimed that, 'Writers are always selling somebody out.'<sup>7</sup> Janet Malcolm has argued that, 'Every journalist who is not too stupid or too full of himself to notice what is going on knows that what he does is indefensible ... he is a kind of confidence man preying on people's vanity, ignorance or loneliness, gaining their trust and betraying them without remorse.'<sup>8</sup> You're not a confidence man, and I'm not vain, nor ignorant, not lonely. And I won't call a small-scale ruse like this 'betrayal': that's far too grandiose a term.

But you've sullied our story, and these stories of ours are much like bodies: they are a fundamental part of who we are. We grow into them, and they shape us. We have to be careful who we allow to access our bodies, and who we tell our stories to. We have to be sure they will be heard, and in the ways we choose. Those who can't speak for themselves need custodians to ensure the safe passage of their stories.

I am the custodian of Amelia's story. My pledge to her is to guard her story and keep it secure. Just as my job is to protect her body. But I failed. I let you into her story. I let you cut it, and stitch it back together in another shape. I let you take something essential from it, something that was never yours to take.

I hope you can take something from me now: a cautionary thought maybe, about truth and disclosure and ownership of story. About voice and vulnerability and value. Not for my sake, but for Amelia's.



## ***That song***

I heard that song again on Sunday night, the one I used to sing to you when you were newborn, when we were alone together, me bathing you or after your feed when you'd look up from my breast, your eyes shining and inchoate as frosted blue glass.

I don't know how I knew that song because it came out before my time. It was planted somewhere in my childhood, then remembered years later in fleeting snatches, as the words and tunes of old songs are. Bright scraps that fit together to form fresh new stories. This one was just for you.

I was watching *Call the Midwife* when I heard it. A farewell party was underway for Chummy, the tall ungainly nurse, who was sailing off to Africa. The song came streaming down the hospital hallway first, then Chummy's scout troop appeared, the boys singing like a heavenly choir. I was transfixed.

*You are my special angel  
Sent from up above  
The Lord smiled down on me  
And sent an angel to love*

It was Chummy's and her husband Peter's favourite love song. Tears welled up in their eyes, and in my eyes too as the voices swelled to a crescendo.

*You are my special angel  
Right from paradise  
I know you're an angel  
Heaven is in your eyes*

Chummy was clapped and hugged, her beaming face taut with apprehension. She was going to work as a missionary in Sierra Leone for six months. At that time, in the 1950s when the show was set, Africa was still very much the dark continent: a world of mystery and otherness, suffering and terror. Chummy was brave to take it on, but it was something she believed she had to do. According to the promos, she would return a changed woman.

When I sang that song to you all those years ago, when I crooned it over you in my very best voice, I had no idea of how important songs would always be to you, how they would be your way of making sense of this world. I was also unaware of the secret meanings lurking behind the lyrics of that song.

That was before our own experience in strange country. The place we went to has been given many names. There's a twee piece that's posted up in hospital wards and therapy rooms and special schools, that does the rounds of parent support groups, and is often quoted in books by mothers. It tells the story of holidaymakers whose trip to Italy is rerouted at the last minute to Holland. We parents of children with disabilities are likened to these tourists, who are upset that their plans have been jettisoned, their hopes dashed. Finally, though, they come to understand that Holland is also a rewarding destination.<sup>9</sup> In another story from one of the many books I've read, a grandfather likens this place to 'a bombed-out beach in Beirut'. But you and I had not planned a trip to Italy or Ireland or Indonesia, and we weren't rerouted to Holland, or Hungary or Hawaii. We didn't end up in Lebanon, dodging landmines. Like Chummy, we went to a dark continent.

Back then, when I first held you close and sang to you, you were my special angel because you were unique, and mine. Later, those words became a code for something else. Special – 'special needs', 'special child', 'special mother' – was a cipher for our difference, our otherness. Angels, too, had new meaning; now they cropped up in the titles of books by and about those special ones, the little flawed beings who were bestowed by God on the saintliest of mothers. That warm, sweet song – our song – soon froze on my lips.

We've returned now from our tour of duty. You've grown up and I've grown older. Like Chummy, I came back changed. I'm not sure it has been for the better, because I don't know who I might have been if I hadn't gone there. For you, there is no such question: you're who you were always meant to be, ever authentic.

When I heard that song on Sunday night, I wanted to strip back all those meanings that had been pinned to those words; I wanted to take it back to what it once had been, a song just for us.

## *In the Garden*

‘No guru, no method, no teacher  
Just you and I and nature  
And the Father in the garden.’

Van Morrison<sup>10</sup>

Eliza is dreaming of a Japanese garden, with sculptured stones set among shapely shrubs and neat green tussocks. She envisages tidy pebble paths, maybe a square of lawn and a leafy tunnel to lead in from the back gate. She sees her fountain working again, a steady stream pouring from the empty water jar of the concrete goddess.

But she is standing in a wasteland, and it is hot and shadeless, and her head pounds with the work of imagining.

She breathes in slowly and deeply and loads a mess of pebbles into a soil sieve, then shakes it hard to release the stubborn flakes of sawdust. Sometime, she hopes, her pebbles will be white and clean again, but right now a layer of brown settles over the yard like forgotten confetti, the end product of recent tree lopping. Behind the scrape of stones, pushing out of an upstairs window, she hears the grinding repetition of Slim Dusty singing *Waltzing Matilda*. She turns to see Daisy’s face at her bedroom window, and figures she has just enough time to shake through one more load before she must go inside to change over the music, and get a drink for Daisy, and make lunch, and then take her daughter out in the car to a park or to the shops.

It’s early January, the dried out end of the holiday rush when heat and boredom settle in to draw the days out, long and flat and drab as dust. Eliza is home with Daisy; the others have scattered now, all with better things to do than shake out debris and take trips to the park. Three weeks it’s been since Daisy’s program closed up shop, and the two of them are alone now with the heat and each other. The first two weeks were fine with the excitement of Christmas, and plenty happening around the house, and people arriving, including Eliza’s sister from the North Coast, Daisy’s favourite person. But now they’ve gone, and Daisy is unravelling as the random days pile up without a clear routine, and Eliza is sliding down into shapelessness. One more slow week to go until Daisy’s program resumes.

Eliza and Daisy are also home with this wreckage of a garden that just a couple of weeks ago was a shady haven. Too shady, too thick with leaves and branches that had become more dangerous than pleasant. The huge jacaranda that sat at the centre of the back yard had overhung the house with its leggy branches, shedding masses of leafy fronds into the roof guttering, its roots probing under the house, seeking to inflict some disaster. The fat trunk of a shaggy eucalypt had overtaken one side of the carport, raining summer-dry gum leaves onto that roof and over the back yard, creating mounds of hazardous leaf-litter. A couple of dead branches way up high on another gum threatened the next door bushman's roof and drove him crazy. Down the front, in the grassy yard that abutted the bush, two self-sown lilly pillies had burgeoned into monsters, one hugging up against the timber deck. There was no escaping it: these trees had to go.

The fires arrived ten weeks ago, and when they came this time, the community was unprepared. It had been so long since the last outbreak, twelve years, that complacency had settled in with its carnival mask of false security. It was too early in the season, too, everyone said: fires in October were unthinkable. But when they came, they were the worst ever.

Eliza was home that hot and windy day, and when she looked out of the window in the early afternoon, she saw a billowing mass of thick black smoke, so very near, and the sun a crying orange disk behind it. The air, screeching with sirens, stank of burning. A text message came through, telling her to prepare to evacuate. She did all she could think of: putting the dog inside, hosing down the house, climbing up onto the roof to fill the gutters. Grabbing passports and photos and laptops. She switched on the radio, and heard them call the fire 'Linksvie', the name of the street next to theirs. Neighbours were scurrying along the verges, with hoses flailing and mobile phones pinned to their ears.

She had to pick Daisy up at three. But there was a roadblock up at the corner, and a long line of stationary cars was snaking into town. Eliza could get up there to meet Daisy's bus on the one open lane, but she would not be able to get back. People from the parked cars were pacing back and forth, anxious about their children and their pets and their homes.

She phoned Kim, Daisy's godmother, who lived on a different side of town, and asked if Daisy could stay there for a couple of hours. She dropped Daisy off and then parked on a car-clogged verge, and walked three kilometres home. Snatches of flames were already flaring up behind houses on the opposite side of her street. She set about preparing the house: clearing out the roof guttering, watering, raking, packing. The blackened sky was alive with helicopters buzzing back and forth, dropping their loads of water and refilling at the lake on the golf course.

With evening approaching, she would have to pick up Daisy. She didn't want to leave the dog alone, so the two of them tramped back up the street, onto the crossroad where the cars were still in lockdown, and back up to the car. They drove to Kim's and got Daisy, and on the way back they had to park even further from home. Eliza had no idea how they would manage: she had Daisy and bags and the dog and a trek of a couple of kilometres ahead of them, in descending dark. But the footpaths were thronging with refugees, and one or two helped her along the way. By the time they turned into their own street, Daisy could barely take another step; she tripped and fell a couple of times, and Eliza had to almost carry her home. Later, her youngest daughter Poppy made it back very late from the city, after a long walk home from the railway station in the smoky dark.

But they were home and safe, unlike the many who found themselves, dazed and disbelieving, in evacuation centres with just the clothes they were wearing. News was scant: the first rumours were that thirty homes had burnt down along the very next ridge. It would be a couple more days before the full extent was known: nearly a hundred homes completely destroyed and countless others damaged. Whole streets had been obliterated.

That night Eliza was woken by Poppy, who dragged her to the window where they saw pockets of red flaring in the dark: the fire had come into their gully. They rang the fire brigade. Fire trucks soon lined the street, and by morning helicopters were circling and dumping their cargo. The firemen assured Eliza that the fire was under control, but she hung about by the back fence as the fire licked at their bush. One of them said, 'Hey lady, haven't you got something else to do?' When she brought coffee down for them, the same one asked about her fire preparations. She told him all the things that she had done: the gutters, the leaf litter, the watering. He said, 'Hey lady, haven't you got a hubby to do that for you?' But she shook her head.

Because Paul had gone. This time, she had to deal with the fires alone.

A couple of weeks later, the streets were strident with the shrieks of chainsaws. People were clearing their yards and cutting down the great gums that lurched over their rooftops, worried that the fires would return to claim whatever had been spared. A Samoan man, a good talker, turned up at her gate: his team was lopping trees down the road, and he offered her a deal. She accepted, and his four big young blokes set to work then and there. The lilly pillies, the shaggy eucalypt, the jacaranda all came down that afternoon. They returned the next day for the branches overhanging the neighbour's, and they trimmed back a straggling maple as well. When they had finished, they stripped off in the carport and swapped their fluoro vests for lava-lavas. Their backs were tattooed with 'Samoa' in curlicues. They took their money, and they left behind them massive piles of cut branches and huge rounds of sliced tree-trunk and a layer of sawdust thick as a snowfall. That was the catch to the deal: they cut, but they didn't take away.

Down the front, with the errant lilly pillies gone, the garden looked newly opened up. But Eliza grieved over the jacaranda-less chaos in the back, as if all that garden's flaws were now laid bare without its shady cloak. And she had all that mess to clear up alone.

Because Paul had gone.

She didn't want to talk about it, how Paul had gone. She didn't want to think about it, what it meant for her life, and Daisy's life, and the lives of her other daughters. It was a wound sharp and deep as the chainsaw scars across the tree stumps in her yard, which the Samoan man had told her to drench with Round-up to stop their shooting up again. It was a weight of debris to be piled up and flattened down, like the mass of severed branches that took up every inch of yard space. But she could get rid of that mess: she hired a truck and enlisted the help of her sister and daughters and a boyfriend and a family friend, and they all piled up the truck to the hilt and took it to the tip.

It was much harder, of course, to deal with Paul's departure.

She could tell you that it's a fact of life for couples who have children with disabilities. She'd read so often that the rate of marriage breakdown is twice what it is for other families. She and Paul used to talk about that, and feel sure that it wouldn't happen to them: they were so secure. But things had broken down some years ago, and they had separated. Then with hope and faith they got back together again, but it hadn't worked out. Eliza knew well that Daisy was only one part of it; that story scraped against and collided with all the other narratives that had shaped their lives, separately and together. Some of those were even more deeply rooted than the one about disability. And she couldn't, or wouldn't, give voice to those. Not here, not now. So she got on with things as best she could.

During that week when the others had gone, Eliza drove down to the Bunnings garden centre in Penrith with Daisy. It was hot and sunny, and they trawled through rows of plants that glistened with water spray. Eliza chose some grasses, blue-green and red-tipped, and a couple of startling succulents. Then she picked out a daphne, the flower named for the spirit of fountains, to plant next to the lady water-carrier. Meanwhile, Daisy stood in the sun under her wide straw hat with her iPod on, and twirled about, flapping her hand in front of face and laughing.

Eliza poked through the plants and read the biographies on tags tied to their stems. She stopped an attendant and asked his advice: she was looking for a small tree to shape for her Japanese garden. He showed her a dwarf lilly pilly with tiny leaves, just right for a topiary. Eliza read its tag. 'This one is too slow-growing,' she said. 'Ah,' he replied in a surprising French accent. 'But for you it ees good. Because wiz ze Japanese garden, you have to make eet slow. Zat ees ze way.'

She freed herself, and left Daisy for a moment while she darted over to the fruit trees in the next aisle. She wanted a weeping cherry, but they were way too expensive, so she settled on an ornamental orange. When she got back to Daisy, an elderly woman was leaning over her, saying, 'Who's looking after you, dearie?' 'I am,' Eliza gasped, and grabbed Daisy's hand. She loaded up the trolley and headed for the check-out, but Daisy didn't want to leave.

Another day they drove up to a big garden ornaments place further up in the mountains because Eliza wanted to buy a temple. But the place was full of lions and

cupids and shepherdesses, and replicas of entombed warriors. It was raining, so Daisy had to stay in the car. Afterwards, they went to a cafe that was steamy inside and Eliza set Daisy up with her music. It took so long to be served that Daisy got restless and noisy, and the other patrons turned to them with scowls that morphed into sugary smiles when their eyes fell on Daisy. Eliza had to beg the waitress to hurry with the milkshake, and when their order finally came, her tea was not hot and her cup was stained but she dared not complain. They drove back home and a great weariness settled over her.

It's not that she doesn't enjoy her time alone with Daisy. It's not that she regrets her caring role, or her lifestyle. But it wears her down. Three weeks ago, even two, she was herself, she thought, in her own skin, but that self had begun to whittle away, a slow, inexorable sanding back that was leaving her edges raw and uncertain. There was no new shape emerging that she could imagine herself into.

So she focuses on the garden: a Zen garden, wrested from the rubble.

She tries to identify Zen people who might help her, as models and exemplars. There's an older Vietnamese man who shares her office at the refugee organisation where she works. He is small and slight and so self-contained that his body could be invisible, but the calm he emanates is large and palpable. People drop by just to feel it, to be touched by it. Eliza knows how hard-won this wisdom of his has been: he spent more than ten years in a re-education camp in the north, up near the Chinese border, after the American War. For the crime of being a government employee in Saigon. Now he lives every day as a blessing.

She thinks of another, more famous person who has made this journey: Aung Sang Suu Kyi, The Lady, under house arrest for so very long, and now a guiding light for democracy, peace, and personal composure. But their lives are too big and unimaginable, she thinks, their hardships and triumphs too heroic.

Still, her mind returns to The Lady and her detainment. House arrest: it's a curious idea. There was a woman whom Eliza remembers reading about, who also found herself under house arrest. She was young, a congregational minister, and she gave up her career, as she was expected to back in the 1950s, to look after her ageing parents. But after a decade of it, she'd had enough. She spoke out, she said that



unmarried daughters like herself were effectively ‘under house arrest’. She set up an advocacy group, and this, they say, provided the groundwork for the Carers Movement in the UK.

The lives of those daughters have surely changed, but that term, ‘house arrest’, worries Eliza. She doesn’t want to admit it, but there are parallels with her own life, how it must fit into confines no wider than her own back yard. But there’s no point in getting upset about it. She could write letters, about the lives of mothers of adult sons and daughters with severe disabilities, and how small the spaces are that they inhabit, and how lonely those places are. She could make a lot of noise and wear herself out over it. She could poison herself with resentment. Or she could just give up and let the sawdust and the dry leaves pile up, and eventually bury her.

She thinks some more about The Lady, about her grace and her acceptance. She thinks about Our Lady, the mother of Jesus, and her terrible burden of suffering, and eventual redemption. Her own task pales in comparison.

The January nights are long and hot, and Eliza sleeps restlessly. She often wakes before dawn, or Daisy wakes her, and snatches of dream-stories are still bright in her mind: images of shaking pebbles and raining debris, of the air thick with smoke or dirt or both, of her and Daisy inside together, staring at the formless world on the other side of the dust-smeared window.

One night she wakes abruptly after a very different kind of dream. She is among shelves of books, probably in a library, scanning through a pile of academic journals as if her life depends on it. The articles she is reading are all about mothers of children with disabilities, by researchers who measure and assess their lives with ratings scales and questionnaires. The pages are thick and misty, and she strains to read them. These researchers make stories about these mothers with difficult phrases that sound like the truth. They use terms like ‘cognitive reframing’ and ‘embrace of paradox’. They write that the competent mothers, the good ones, are the ones who recognise that their lives are more meaningful because of their disabled children and their caring obligations. In fact, the greater these demands, the researchers report, the greater the opportunity for the mothers to grow personally. To be better. These mothers can, if they are good enough, and their children disabled enough, find redemption and transcendence.

Eliza panics. She isn't ready to be one of these mothers. She isn't clean and pure enough. Dirt clings to her.

In the morning, Eliza uses her will to banish the dream-demons: the researchers and their words and their stories. After breakfast, she gets Daisy dressed and takes her down the steps to the back garden with her music and her hat, and she sits her on an old wrought-iron chair in the shade. After Eliza has watered the new plants in their pots by the door, she will lay the clean pebbles out and then rake through the woodchips in the garden beds. After that, she will hunt around the garden for rocks to replace the damaged ones along the borders of the paths. Tomorrow, all going well, she will begin the planting.

She feels better now that the garden is taking shape. Its bones are good and strong. With the jacaranda gone, a jade tree that was in its shadow has found new life. Along its elegant branches, small succulent leaves reach out for new-found sunlight. An azalea, once hidden, now reveals its unusual oriental planes. Out the back, there are some large sandstone rocks that can stand like sentinels among the plants, but she will have to get some help to move them.

When the garden is finished, she will sit on the iron chairs with Daisy, and she will drink tea while Daisy has her chocolate milk. She knows this will never be a real Japanese garden: the bush will always push against its boundaries: wiry natives will sprout up like wily intruders, and eucalyptus leaves will continue to fall, disrupting its order.

Maybe she can place some of the bird mosaics that are stacked somewhere inside out here, too, and their shiny tile-shards will catch the sun.

Ah, she thinks, there's still so much work to be done.

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## Notes

<sup>1</sup> Candia McWilliam. 2010. *What to Look for in Winter: a Memoir in Blindness*. London: Jonathon Cape.

<sup>2</sup> These paintings by Pablo Picasso are, respectively: *Nude in black chair* (1932), *Woman in an armchair* (1929), *Nude in an armchair* (1959), *Nude in an armchair* (1932).

<sup>3</sup> After three long years at that school, Amelia transfers to another where he needs are better met. This is described in the chapter, 'New school', in the full memoir .

<sup>4</sup> A version of this story was published in *Griffith REVIEW 45* Companion E-book, pages 30-40. [https://griffithreview.com/wp-content/uploads/GriffithREVIEW45\\_WWK.pdf](https://griffithreview.com/wp-content/uploads/GriffithREVIEW45_WWK.pdf)

<sup>5</sup> From 'Die Heilige' [The Saint] in Susan Ranson and Marielle Sutherland (trans). 2011. *Rainer Maria Rilke: Selected Poems*. Oxford: Oxford University Press.

<sup>6</sup> Julia Kristeva. 1982. *Powers of Horror: An Essay in Abjection*. New York: Columbia University Press.

<sup>7</sup> Joan Didion. 1968. *Slouching Towards Bethlehem*. New York: Farrar, Straus and Giroux.

<sup>8</sup> Janet Malcolm. 1990. *The Journalist and the Murderer*. New York: Knopf.

<sup>9</sup> 'Welcome to Holland' by Emily Perl Kingsley (first published 1987) appears in Stanley L. Klein and Kim Schive, eds. 2001. *You Will Dream New Dreams*. New York: Kensington Books.

<sup>10</sup> 'In the Garden' is from Morrison's 1986 album, *No Guru, No Method, No Teacher*.