

TUESDAY'S Child

From the moment of the bombshell diagnosis, Kathy Evans has battled to reclaim her daughter's individuality from the impersonal grasp of Down syndrome

THE STORY OF MY LIFE with Caoimhe began with fear. Only the first nine hours of her existence remain untainted. Over the ensuing months, the fear changed in size and intensity like the sun's shadow, and although there have been times when it shrinks to virtually nothing, I doubt it will ever truly disappear.

In those early days I would look down at her and see a beautiful baby, delicate as a bubble, and be filled with a pristine love. But fear has no time for the present; it lurks among the dark shapes and alleyways of the future. And there was plenty out there to foster it.

Caoimhe with her family outside their old home in Brighton, Melbourne. Left to right: Ceridwen (Wynn), Conor, Eleanor (Ellie), Caoimhe and Kathy

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TUESDAY'S CHILD

I learnt early on that fear wears an impersonal face. Only minutes after her diagnosis with Down syndrome, the doctor who'd delivered Caoimhe (pronounced Keeva) – who had measured the hill of my bump over changing seasons while chatting about football practice and muddy boots, her presence warm and comforting – was talking awkwardly about Caoimhe's "intellectual deficit". The thin prelude of my daughter's life as a result was marred by tests: echocardiograms on her heart; heels poked, prodded and squeezed for droplets of reluctant blood; bald head scrubbed for the attachment of electrodes. The violence of it all appalled me.

And to compound the insult, printed fact sheets laid out the stark chronology of my child's future: respiratory infections and an increased risk of leukaemia in childhood; hearing and sight problems; thyroid malfunction; and an early death at around 55. According to the literature, the perfect shell of her newborn body would soon split and crack as she grew awkwardly, revealing an underdeveloped nasal bone, a large tongue, small genitalia, mottled skin and short arms and legs.

I remember at some point the nurse who had given me these leaflets telling me, "Really, she's just like your other two children – she'll do everything that they do, only slower," and I puzzled at the absurdity of her statement. After the births of my older girls, Ellie and Wynnie, now aged 11 and 7, no-one had sat down and made a prognosis of their future: broken bones, anorexia, followed by addictions to illicit substances and possible heart failure in old age. And while I know that we all exist at random, that the spectre of death can single us out at any time, I had a mental script of how their lives would progress: school, university, marriage, kids – but not necessarily in that order. The outline of Caoimhe's future was one I had never come across.

Over the decades, scientists have gained an intimate knowledge of chromosome 21 and the 200-400 genes that live there. They know how an extra copy of the chromosome clogs the brain's circuit board, overloading it with enzymes and proteins so that, like the mad wizard vainly managing the controls of his own effigy in the land of Oz, wires become crossed and messages confused. While I am perversely grateful that this information allows me to be alert and prepared, I am aware that the same knowledge steals something of the magic of not knowing. Caoimhe's future is not an exciting blank page; there are already too many notes scribbled in the margin.

She will not do everything my other children are able to do. She will not lose herself in the rich, infinite landscape of higher learning, nor be gripped by wanderlust and travel the world with a backpack. She will not be a single silhouette on a Balinese beach, or trek solo through a rainforest drinking water she boiled herself on a campfire. She won't stand bemused, clutching a timetable in the middle of a dusty, chaotic Indian railway station.

I found the modern jargon used to describe Caoimhe's condition baffling. "Retarded" was not a word in use any more; it was replaced with "developmental delay". This inspired hope, as if, like a train running behind schedule, Caoimhe's ordinary skills would arrive eventually. While I had no doubt the basic, mechanical ones would, it was the complex, cerebral ones I grieved for. Both friends and professionals urged me to focus on the positives without dwelling on her limits, as if regret and hope, pleasure and disappointment could not coexist within my consciousness. The pendulum swung between minimising her condition and magnifying it to frightening proportions.

People did not know how to react to Caoimhe's birth, either, uncertain whether to offer their congratulations or commiserations. Some did the first, some the latter, and the more sensitive did both. One well-meaning person sent me a eulogy from someone's funeral that she thought would be appreciated, but I'd just given birth! This is life, goddamnit. Not life as we know it, but life all the same.

WHEN I GOT HOME I CRIED BUCKETS FOR ALL THE AVERTED GAZES, SNIGGERS AND WHISPERS MY CHILD HAD YET TO MEET



PHOTOS: COURTESY OF KATHY EVANS

My partner Conor and I lost count of the number of comments about children with Down syndrome being "happy". We received this old cliché with the same damp enthusiasm as a consolation prize on school sports day. No parent wants their child relegated to a homogeneous group of happy half-wits, without personalities of their own. What was worse than these tactless though well-meaning remarks were the friends who said nothing.

When Caoimhe was six weeks old and the ache of grief still stiff in my bones, I slowly and painfully began to circulate.

One of those early outings was to a birthday party where Caoimhe's diagnosis was never mentioned. People came over to chat politely, then flittered away like butterflies in search of something brighter, tastier. I met a woman from my birthing classes whose baby had been born just a few weeks before Caoimhe. Our chatter was formal and awkward, like that of foreigners handicapped by different mother tongues. When the moment of escape came at last, by way of her baby's squawks of hunger, we both smiled at one another, relieved to be rid of the burden of pretence.

What do you say to a mother in a bipolar state of joy and grief? In cases of stillbirth, there is the solid, indisputable evidence of a body, lifeless but real. But when the baby is born alive, albeit disabled, there is confusion; many of my friends were willing to share in my delight but skirted shyly around my grief for the baby I hadn't had. I crackled and popped like a firework, set off by the slightest comment. Perhaps they were frightened of saying the wrong thing, but silence was worse.

When Caoimhe was a few months old, we arranged to meet several families we had known for some years at an open-air symphony in a suburban park. It was typical Melbourne weather: the day started hot and bright, but by the time the orchestra was to start, the air was melancholy and fat with rain. While the children played together at the front of the stage, we hunkered down on damp tartan rugs and busied ourselves with our picnics. Next to us, Caoimhe lay in her pram, her starfish hands making fists at the trees. And then came the slow, sinking realisation:

Left: Wynnie, then six, Caoimhe, three, and Ellie, ten, in County Down, Northern Ireland

Below, Kathy with Caoimhe, then almost three, at a picnic in Northern Ireland



we were being ignored. One of the couples, pregnant with their second child, was deliberately avoiding us.

Conor and I held a low, brief tactics meeting. My husband would mind Caoimhe while I steeled myself to approach the female, unencumbered by the blight of my daughter. This I did. Conversation was bright and artificial and revolved around her pregnancy. Not once did she ask after my baby. I tried to bear in mind that she may have had fears about her own pregnancy, but it still hurt. When I got home I cried buckets for all the averted gazes, blank stares, sniggers and whispers that my child had yet to meet.

Those unpleasant though thankfully isolated encounters shook me deeply. Only in our immediate circle of close friends where Caoimhe was accepted without question could I feel safe. Venturing outside the confines of their security compound required me to psyche myself up. Like an army major, I would go through the drill: thoughtless comments, sideways stares spoke volumes about them, not us. *They have the problem*, I would tell myself over and over like a mantra. But the truth is, I didn't believe it.

Why are we so uncomfortable in the presence of disability? Perhaps because it serves to remind us of our own destructibility, and because of this we don't want to acknowledge its existence, despite the statistics that tell you 10% of the population has some form of handicap. But in a world where perfection matters, people with differences are like ghosts: they are all around us but can be seen by only a few. Disability is society's blind spot, and now that the scales have fallen from my eyes, I can see its injustices everywhere.

Once, when Caoimhe was having a blood test at the Children's Hospital, the nurse struggled to find a vein in Caoimhe's small, plump arm. "Down's kids are all like this," she muttered. "Bad veins."

I pointed out that I too have deep veins and it once took a nurse five

attempts to draw blood, suggesting Caoimhe may have simply inherited my reluctant vessels. But she didn't pay me any attention and continued to take aim and jab as if she was playing darts. I wrestled Caoimhe from her grip; we would try another nurse another day. Her parting words were, "You'd better get used to this. Down's kids have blood tests all the time."

Whatever Caoimhe did or didn't do was as a result of Down syndrome, it

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seemed. Delayed teeth, delayed walking, snoring, bizarre sleeping postures, love of music, sunny nature and big dribbly kisses came under its jurisdiction. Nothing was left for her. She was not an individual, a child as unique as her own thumbprint; she was of a different species, bearing identifying hallmarks which separated her from the rest of the human race and required careful handling by experts other than her mother.

There were, of course, among the abundance of health professionals we saw, those who by remarking on a unique characteristic allowed me to savour the taste of parental pride. In these moments, when it was hair or eyes or skin being admired, she was deliciously ordinary.

But one nurse particularly annoyed me, ending each visit with a compliment about what a wonderful job I was

doing. I figured this praise was supposed to spur me on so that I would wake up the next day with renewed vigour for the herculean task of raising a child with a disability.

I NEED THE RAW tattered edges of emotion, not synthetic sentiment, and go looking for books that may offer some guidance in unravelling the mystery of my child. In my local library I find only three volumes, squeezed in at the end of a burgeoning pregnancy and motherhood section like an uncomfortable afterthought. The first is from something called the "Special Needs Collection" and, inside, the introduction warns: "No book can mend a broken heart or shattered dreams." I see the two jagged pieces of my own heart, ruby red as a valentine's, lying among scattered bits of coloured paper.

I drift through the contents and turn to "Your Child with Down Syndrome and Your Marriage", because this is an anxiety as yet unexplored; an uneasiness that, while not invading regular head space, sits like an anchored pirate ship, just left of the safety zone.

The author, an educator, warns that children with special needs can put a strain on their parents' relationship and a way to deal with this is to "identify ways in which you have coped with other difficult situations in your lives. Use these same strategies in dealing with the special needs of your child with Down syndrome."

I think back to the time Conor and I moved to Australia, pregnant, jobless and penniless. I'd cried many tears and smashed many mugs we could ill afford to break. But comparing the two situations seemed as fruitless as the proverbial apples and pears.

I turn to chapter six, "Your Baby's Development", and read about how important it is for me to be involved in Caoimhe's life, to "maximise her potential". I read this while my daughter lies in her cot babbling to a stuffed unicorn

and I feel the twang of guilt's muscle. I go into the bedroom and make the unicorn dance and sing. Caoimhe looks at me, puzzled, curious, a half-smile playing on her lips. I leave her and return to "Developmental Milestones".

I descend the stern black bullet points with the nervousness of a student scanning an exam paper, mentally ticking off the ones she has passed, simultaneously constructing new fantasies from the shrapnel of a future bombed to smithereens. Caoimhe would be the first child with Down's to graduate from Monash University. She'd be a raging beauty, Miss Down's Universe... and I topple these dreams with my own hand, like a rageful toddler.

Hope is built from books but smashed by reality. Chapter six goes on to quote a study of children with Down syndrome who took part in an early intervention programme at an American university and, as a result, reached some developmental milestones "faster than the normal child". My goal as a parent, the book says, "is to maximise strengths and minimise weaknesses so that your child will realise her fullest potential".

I think of my child supine in her cot while I sit reading about her, an armchair mother. I am failing her. I close the book.

EVERY WAKING MOMENT, I grapple with the paradox of my love for Caoimhe and my fear of her difference. It is as if birth had stirred up schoolyard prejudices I thought I'd successfully buried; I never knew, until now, how much I needed to conform.

Caoimhe is my stigma, the placard that declares our family defective. Once we strolled out with our two beautiful girls and were greeted with admiring smiles and comments, gazed upon favourably like some impressionist work of art. Now there is a rip in the tableau, as if someone has come along

Caoimhe, aged three, snapped by Ellie in the field behind their new home in County Down



and splattered it with ink, or taken a knife to it, and in doing so, revealed what we had managed to conceal for so long: that we are not picture-perfect.

Now when I venture out, my chin juts just a little bit more, my demeanour is slightly defensive as I guard myself instinctively against those whose mistakes are not so visible. It is so much harder in this consumer-crazed bubble of wealth where I live, this bayside suburb of Melbourne where A-grade children are the ultimate commodity and twins come late in life from a test tube, selected, screened and sterilised like jars of baby food.

But there is something else happening, and it's something good. I am becoming more conscious of my own

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appearance. My clothes are becoming brighter; there are colours and ribbons

and tribal painted skirts instead of the worthy polar fleeces and sombre tones that hide stains. I bin a bottle-green cardigan. I hate it. I raid the junk shops for lime-green trousers, purple striped flares, glittery orange tops. The colours clash. My hair grows long and I wear it in plaits from which bits keep escaping. My eldest daughter is alarmed by the change and aches for the familiar mum in the sensible jeans with the controllable haircut. But I am straining at the binds of motherhood, impatient to discover what for so long has been lost: colour, youth, gaiety. In another of life's contradictions, having Caoimhe has unearthed something that got buried after the first birth: a sensuality that went underground as I dutifully

PHOTO: COURTESY OF KATHY EVANS

donned, with just a small sigh, the drab garb of motherhood.

One day I take Caoimhe to a new playgroup in the wealthy suburb where I live. As we sit in a ring apart from our children I feel panic palpable in my chest. The talk is about the playgroup vacuum cleaner. It has broken down again. I look at Caoimhe on the other side of the room playing with a mess of musical instruments. She is a sticky contrast to the neat white heads of the other children: there is a sock missing and snot, thick as treacle, trickles from both nostrils. Her pigtailed are stiff with porridge. She catches me smiling at her and grins back, her face alive with the raw, unburnished act of living.

The look she gives me is so vibrant, so strong, I shrink from it. I am weak with the responsibility of defending this moment, of fighting off experiences that may dull the radiance. I am aware that the best way to protect her is to protect myself, to fight for the prize of an adult sexuality and hang on to it, grimly, determinedly, in a society all too keen to diminish it.

I have read about yummy mummies and I don't want to be one. But neither do I want to be the "mother of a child with Down syndrome". I remember a friend remarking to me that I didn't look like a mother of a child with Down's, and I had to stop and think about that statement.

What was such a woman supposed to look like, I asked my friend. "Grey," she told me. "Sensible. Elasticated." The message was clear: she is old, sad and about as sexual as a leaking bucket.

Perhaps, then, this re-emergence of a younger, more colourful imprint of myself is nothing more than a defiant attempt to buck the trend, a pathetic fuck-you gesture to the world. Perhaps it was merely a bid to separate myself from my flawed child, to put some distance between us so that the label of her disability does not attach itself to me.

Who knows? I was brought up to believe that sexuality was something to be feared, and in mothers abhorred. As

a teenager I railed against the constraints of my convent school. I spent many an hour arguing heatedly over the religious nonsense of a sexless Madonna, but slowly and blindly I have succumbed to her magnetic force.

I am up to my neck in the mire of motherhood and only now am I aware of the disparity between what the mouth has been saying and the way I have been living. My appearance, my career, my preoccupations with cleanliness, sterilising, cooking, the state of the toilet, the need to have everything perfect: I see now that they mask an anxiety about how to be a mother and remain sexual.

I am alarmed at how close I am to being totally submerged in a culture I blithely vowed would not change me. How did this happen? How can the intelligence remain firm in one set of beliefs and the subconscious fixed in another? I see a yawning gap between my emotional and intellectual life, a chasm I must work to close, and the task is daunting.

I never went back to that playgroup, unable to face the expensive tracksuits, the shiny nails and dyed blonde hair. I do not fully understand how Caoimhe's birth has reawakened this dormant sexuality, but I am grateful to my daughter. She may be the symbol of a flawed union, of an ageing body, but she has delivered a message from my soul and freed me from my past.

She is not part of a picture-book society, full of toddlers with neat white-blond hair and bright jelly-sweet clothes, perfectly ironed, but my love for her at this moment is unswerving, undiminished. It has taken me a while to learn to love my body again after the crush of failure, but I do with a new tenderness. I am kinder to myself.

This is what Caoimhe has taught me. Learning to love her has taught me how to love myself. +

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