

PRAISE FOR *MALACHY: A FATHER'S STORY OF LOVE, LAUGHTER AND LOSS*

The beautiful boy staring out from the book cover was sunshine itself.

I was lucky to meet Malachy in an all too familiar setting for Maggie and Dom, at Sydney's Westmead hospital. Malachy stole your heart in an instant. He'd be very proud of his Dad and his family, who have crafted an exquisite tribute to his remarkable life. With an eloquence and insight that comes in part from overwhelming pain and loss, Dom has written a book that speaks to all the complexities of the human experience. This is so much more than a guidebook to being the parents of a Heartkid; it's a deeply profound memoir about the meaning of life.

In his life, Malachy bestowed his special gifts on everyone who knew him. With this magnificent book, Dom conveys the Malachy magic to all, reminding us again that we can never take a single day for granted.

—Simon Reeve, television presenter, journalist,
podcaster and HeartKids Ambassador

All around us, though we don't always know it, are parents whose children are not well. Who have anguish and grief mixed with the normal travails of raising a child. Some of these parents become able to rise up through that and muster an extra lovingness that means a hard life, or a tragically short life, can still be a beautiful one. Suffering doesn't have to break us. It can teach us to love. A beautifully written book about a beautifully loved child: this family did something special under huge stress, and we can all take heart from it.

—Steve Biddulph AM, bestselling parenting author whose books include *Manhood*, *Fully Human* and *Raising Boys*

A beautiful book and an eye-opener for all of us involved in the care of children with heart problems. Always well-intentioned

but often messy, their story is a good reminder of how we can improve. Dom and Maggie's relationship with Malachy, and their investment of precious time in the development of HeartKids, both have interesting back stories.

Their loss is enormous. Dom's thoughtful humanity shines as a guiding light throughout.

—David Winlaw, Professor of Surgery, cardiothoracic surgeon, researcher, Cincinnati Children's Hospital Medical Center

Dominic Frawley's loving elegy to his cherished son is deeply moving. It is a beautiful celebration of young Malachy's life and the family who adored him. As it moves from heart-warming to heart-rending ... to heart-wrenching, there are also moments where you will laugh out loud. ('They're crying! Get the social worker!' had me chortling and smiling for some time.) Ultimately, *Malachy* is a supremely uplifting story of an irrepressible soul, beloved forever and immortalised in this tribute.

—Cindy Pan, medical practitioner, bestselling author, media personality

Joy and grief, philosophy and faith, and the everlasting bond between father and son. Through one life, Frawley explores the things that make us – and almost break us.

—Allison Tait (A.L. Tait), bestselling author middle-grade adventure series *The Mapmaker Chronicles* and the *Ateban Cipher*, and her new novel *The Fire Star*

Malachy: A father's story of love, laughter and loss is an unforgettable experience. Dom's sensitive and gifted writing style engaged me from the very beginning so that I felt as if I was involved heart and soul in the journey of Malachy's lifetime. The family dynamic that was created by six intelligent, creative, generous, loving and adventurous people enabled Malachy to achieve his potential as a human being for fourteen plus years; to pack into those years more quality of life than many folk do if they live to be a hundred. Dom enables the reader to experience his son undefended, to see the

world through his eyes, so I feel as if I know him, and as if I know his beautiful family.

‘Words are our tools of resurrection’ is a quote I love from a character in a book by Pip Williams, *The Dictionary of Lost Words*. Dom has used his words of love, loss and grief beautifully to do just that – to bring Malachy back into life again, into his life, and into the lives of everyone who has the courage to fully experience this touching tribute to a precious son.

—Dianne McKissock OAM, sociologist, relationship counsellor, and grief therapist, Co-Founder and Patron of the Bereavement Care Centre and the National Centre for Childhood Grief, author of *Coping with Grief*

This is a very interesting book. It details the very close relationship between a father and son, perhaps intensified by the fact that Malachy had a major cardiac anomaly. On that level it provides an insight into the effect of a major illness on a family and the interactions that result from that. On another level however it clarifies the impact of a serious cardiac condition on the child and his place in the world.

While only a very small percentage of children with heart conditions are affected in this way, I think this book informs both the medical community and the patient group on this interaction and provides a very valuable insight into the effect of severe heart disease on the child, the family and his community. From my point of view it clarifies aspects of the doctor/patient relationship from the patient’s perspective: an area that undoubtedly warrants further examination!

This is a “must read” for all medical professionals looking after patients like Malachy. It is likely to be of interest to other parents of children with severe cardiac conditions and particularly to potential parents in whom a cardiac condition has been identified antenatally. I would hope that a book like this enables us to improve our support of such families through a journey that at times can be extremely difficult.

—Stephen Cooper, paediatric cardiologist



MALACHY

*A father's story of love,
laughter and loss*

DOMINIC FRAWLEY



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*For and with Malachy, age fourteen.
He wanted to publish his first book by fifteen.*

Disclaimer

Every care has been taken to verify names, dates and details throughout this book. But, as much is reliant on memory, some unintentional errors may have occurred. The Publisher assumes no legal liability or responsibility for inaccuracies; they do, however, welcome any information that will redress them.

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MAGGIE'S DREAM

Such is the life of a man. Moments of joy, obliterated by unforgettable sadness. There's no need to tell the children that.

— Marcel Pagnol

Organised chaos surrounds me at my desk. The familiarity of my personal mess is a comfort to me, as my gaze settles on the neighbour's camphor laurel tree. I am thinking about my family. At 49 years of age I am making the standard adjustments every parent makes to the emptying of my family nest. My children have each forged their own futures. There is only one thing, one moment I would change.

Sometimes I want the world to stop, but not as desperately as I once did, and not for such long periods of time. People who have children believe the children make them happy. My elder daughter, Imogen, likes to remind me that the studies tell a different story. The childless report higher happiness scores on average than their fertile peers.

I try not to feel bleak. Against the evidence of my own experience, I believe happiness lies in our deepest bonds. Maggie, my wife, had this dream of our children last night:

A musty aromatic spice floats in the humid air of the restaurant. Bland cover versions of once popular tunes mingle with the scattered voices of the diners, whose cutlery clinks against patterned ceramic bowls.

Dark red carpet seems to suck the ambient light issuing from a handful of Chinese lanterns, providing dull illumination for the quiet dinnertime crowd. At one table, a mother and three children are playing out a familiar family scene. The four of them are playing our family 'question game', designed to

Maggie's dream

occupy and entertain the children while our food is prepared. Each person takes a turn at posing a bespoke trivia question to each of their dinner companions. Usually, the parents build learning points into their questions.

Maggie, dressed in her usual flowing, post-hippie style, is smiling. Laughter breaks out intermittently as the familial banter shifts back and forth. Her unfurrowed brow moves to engage each child in turn.

On Maggie's left is a slender, fair little girl. White-blond hair sits neatly at the nape of her neck as she cranes energetically forward, eyes wide. This is Niamh, who in the dream looks six years old. As Maggie speaks, the little girl's eyebrows jump with surprise, her mouth forms an 'O', excitement plain to see.

An olive-skinned boy of eight murmurs something, drawing Maggie's attention to the next seat at the table, as the waitress delivers a bowl of steamed dim sims. Loose brown curls frame a cheeky grin as with one eye cocked, the boy focuses on his mother. This eight-year-old is Seamus. Maggie holds his attention, clearly the conversation is riveting to him too. Seamus's mouth drops open as his sister's had only seconds ago. Jokes spill across the table while the dinner progresses.

As Niamh and Seamus sit back to enjoy reflecting on Maggie's questions there is a brief lull in the conversation. The scene moves to the other diner, the smallest of them, lighter in colour than his brother, finely shaped like his sister. Malachy is bursting with animation and grinning widely. There is a blue tinge to his four-year-old lips as he laughs and enjoys whatever amazing revelations his mother is making.

Having left the older two to their ruminations, Maggie is now merrily focused on Malachy. His delight is palpable, pushing his way onto Mum's knee, ever one for physical contact. Dishevelled locks of light brown hair, with touches of blonde and ginger, fall this way and that. Spare shoulders hunch forward under his T-shirt. The pre-school child confidently stares up at Maggie, utters something to draw

laughter and waits for her rejoinder. Maggie begins to speak, but falters. Puzzled, she starts again. The children's faces turn blank. Silence descends. The dream vanishes.

I jolted awake as Maggie's sobs cut through the night. I was barely asleep anyway, nursing my own sorrows through the dark of the early hours. Shaken by Maggie's sudden distress it took me a few seconds to realise what was going on.

'I'm here, Maggie.' I waited.

'I've had the worst dream,' Maggie groaned.

'Do you want to tell me about it?'

In the bedside light Maggie looked gaunt and expressionless. We caught eyes, no doubt my stare every bit as hollow as hers.

'I was at the Chinese restaurant, with the children. Just the little three. You and Imogen weren't there. I felt so happy. They were little again. We were at Nowra Palace.'

Pausing, Maggie inhaled.

'So, I was talking to them, and I realised they were younger, but I wasn't. So, it dawned on me I was back in time and they'd be keen to hear about the future.'

'Guys, this is cool, do you get it? I am nearly 50, but you're still young, so I can tell you about the future.'

'Of course, they wanted to know all sorts of things, so I was filling them in. I started with Niamh.'

'Niamh, you're growing up heaps. You're at boarding school in Sydney. You're doing your HSC, darling. You're taller than me, with long blond hair. You're still a beautiful runner. You like music and art. You're planning to go off to uni next year.'

It was exciting. We were all excited because I knew all this stuff they hadn't been through yet. Then I told Seamus: 'Seamus, you're all grown up. You're 20, and as tall as Dom. You've got a huge mop of hair! You're at uni already. You're studying medicine, and you live in Sydney with Imogen. You've got some really great friends.'

Maggie's dream

Another pause, another breath, deep, and a shake of her head.

'I told them how I teach at St John's now, and that they all went to school there for a while, and that you're still working down the road, and we still live in Nowra. It was so lovely being back in that time.

I felt so happy. Then Malachy was being all cute and quirky, and of course he asked me about himself. I started telling him: 'Malachy, you're getting so tall, too; you go to high school and your hair is getting a bit curly. You've been learning the drums. You love to write and ... you catch the bus, you even have your own YouTube channel ... and—'

'Then in the dream I remembered what had happened. I couldn't tell them. I realised what had happened, and I froze. Something was wrong. That's when I woke up. I couldn't tell them. I couldn't tell Malachy.'

Our hands clutching, we stared at the ceiling in the semi-darkness of our bedroom. No further words were needed.

I know, and Maggie knows, what it was in her dream. What it was she couldn't tell the children.

PART 1

INFANCY

The primordial soup

1

AN ULTRASOUND

We do not remember days. We remember moments.

— Cesare Pavese

Malachy is an Irish name, derived from the Hebrew, Malachi: Messenger of God. If our son Malachy had a message from above, we were destined to have a hard time deciphering just what it was. ‘What if?’ was a question he would pose time and time again, starting months before his birth.

Maggie had a routine ultrasound test 19 weeks into her fourth pregnancy. To this point, ultrasound had been a reliable source of good news in our family. The first glimpse of reproduced life in utero always has an air of the miraculous about it.

Ultrasound technology had been in rapid evolution through my lifetime. It was first used to look at human organs in the late 1940s, including the heart in the 1950s, then in the 1960s for measurement of foetal skulls during pregnancy. Constant progress had spread the technology around the world, including into the lounge room of my childhood home. I remember as a child in the 1970s marvelling when my father, a vascular surgeon, had demonstrated a portable ‘Pencil Doppler’ on the artery in my wrist. He told me his ‘toy’ was the first such device imported into Australia. I was intrigued by his explanation that this pen-like appliance bounced sound waves into my body to measure the rush of blood through my vessels.

The very first pregnancy ultrasound I ever saw was part of my medical studies in the 1980s. At that point in history the images were still rudimentary. The grainy pictures relied more on scientific interpretation than keen eyesight. A faint blur near some leg-like shadows was used to guess the gender of the foetus. A fluttering orb in the foetal chest confirmed a heartbeat.

My second ultrasound experience arrived during Maggie's gestation of our eldest child, Imogen. I vividly recall the first moment, in 1993, when Imogen's heartbeat was transmitted into the sterile air of a consulting room in North Sydney. Maggie and I were startled to hear her tiny heart racing along, with a loud rushing sound bouncing around the room. Maggie nearly leapt from the couch as this new life burst from theory into reality. It was only in that moment that we truly believed that the delay in Maggie's cycle, and the faint blue line on a pregnancy test kit, really was a new, separate, life within.

As Maggie and I moved through the 1990s, having four babies along the way, the ultrasound pictures grew clearer with each successive pregnancy.

Ultrasound number three belongs to Seamus. Now experienced parents, we were less startled by the images, but as with Imogen's earlier study, the ultrasound for Seamus led to a bout of self-congratulation.

After Seamus was Niamh. Her foetal ultrasound, number four in my experience, ran to plan. The full range of views and measurements were hastily ticked off in a darkened room. Once more Maggie and I confirmed our great fecundity and revelled in the perfection of another delicate, prized offspring.

By 1998, so much detail could be assessed in the hands of the right operator, that all manner of malformations and anomalies, speeds of growth, and volumes of fluid and tissue could be assessed and recorded. We had even had the joy of recognising facial features in our unborn children or imagining a slight wave of the hand or curling of the upper lip to 'smile for the camera'.

An ultrasound

In the spring of 1998, Maggie and I attended Malachy's ultrasound with an air of complacent affability. After our previous successes there was hardly a thought given to anything but the miraculous nature of human reproduction. Mother Nature seemed very adept in the manufacture and production of our babies. Professional murmurs about normal organs and correct counts of fingers and toes were the familiar background music of ultrasonography. We knew the antenatal routine: pokes and prods, then reassurance, followed by celebration.

After introductions Maggie mounted the bed. The ambient light was dimmed, and a dollop of clear jelly was squirted onto her maternally swollen tummy. She wriggled slightly—it's always a bit colder than expected. With practised skill, and just the necessary amount of small talk, the sonographer went about her intimate work. A smooth transducer was pressed against Maggie's skin, bouncing its sound waves in to throw images onto the screen. Here are the legs, and here the arms. Fingers and toes, size of the head, the growth just right for the stated number of weeks. Holding hands, smiling with confidence, Maggie and I alternately glanced at each other and at the screen. The beam was pointed at the heart. We watched a rhythmic series of wave forms, little pointed bumps, stream across the screen. Some waves looked bigger than others. That was unfamiliar. I didn't remember that from the other ultrasounds I had seen.

In the darkened room, watching the grey and white forms scroll across the screen, a fleeting moment had departed from the script.

Foreboding crept up on me. I scanned my memories of previous ultrasounds, trying to reassure myself that the images on the screen were normal.

But something was wrong.

My heart paused, afraid, behind my ribs. Time stood still. A sudden tight seal held the dark room adrift from the ordinary passage of life. I felt a gripping in my chest as the world seemed to empty of everything but the question at hand. A confused mixture

of déjà vu and half-remembered images blended to produce uncertainty, and fear.

I struggled to voice my unease: 'Uh ... umm... Is... Excuse me? Is that ... normal? It looks a bit ... Is that wave a bit ... small?'

The sonographer, glancing my way, paused to clarify the question, as I pointed at the screen. She tilted her head and waited for me to speak. Nervous, I rephrased the question in my mind, before wondering aloud, 'Isn't the, is the, the amplitude of that heart signal ... a bit low?'

'No,' the woman paused, 'it's all okay'. Adjusting her hands slightly. 'I think it's just the angle of the transducer.' She manipulated the probe for another look. 'You can see there's a normal heartbeat there. We had a nice four-chamber view just before.'

The experienced sonographer was unruffled. My choking feeling faded. Her murmured reassurance was effective. My alarm, I reminded myself, was based on very limited experience. The moment passed. Restart the clock—unfreeze the time, we're back at our breeding best! My unease grew faint in a handful of seconds. Breath returned and smiling resumed.

That one moment, suffused with destiny, sank back to join countless others in the file of obscured memories. Most of those memories will never be retrieved. That one moment is with me now, at my desk. It forces its way back. What if I'd acted then and there to demand a closer look or a second opinion? What if I'd been decisive and trusted my gut feeling? What if I had declined to be reassured?

If I had more experience with ultrasound, could I have known what was in store? Could we have been better prepared?

That frozen moment belongs in a cluster of dysphoric flashbacks; a set of destructive memories. They are labelled by their type: THE WHAT IFs.

2

IT'S A BOY

*Things which matter most must never be at the mercy
of things which matter least.*

— Goethe

Embarrassing stories about President Bill Clinton flooded the media for months on end, but in February 1999 he was acquitted by the Senate in his impeachment trial. That same month, Eminem released his first major album, *The Slim Shady LP*. By March, Roberto Benigni and Gwyneth Paltrow were preparing to accept the Academy Awards for Best Actor and Best Actress, for their roles in *Life is Beautiful* and *Shakespeare in Love*, respectively.

Meanwhile in Australia, Maggie Frawley went through the nesting process one more time, for an event of much greater importance in our lives. The second day of March would see the birth of our fourth and youngest child, Malachy Declan Mandela Frawley. Feeling quite certain this would end our breeding season, we couldn't resist slipping in a tip of the hat to Nelson Mandela, the great freedom fighter of our lifetime.

Myriad challenges no doubt beset our young family every day through that period, but none of them weighed on us unduly. The future was unquestionably ours to grasp, and with four young children in tow (very shortly) we had neither the time nor the inclination to doubt our readiness for the grand adventure ahead.

They were peaceful days, but there was a freight train heading our way, the rushing fury and power of its approach inexplicably silent. Any gods watching must have stared through the cracks between their spectral fingers, dismayed at our blissful lack of anticipation.

The labour to deliver Malachy, undertaken at our local district hospital, was strenuous but uneventful. Maggie had hoped for that easy brisk delivery we'd had friends speak of, but not yet experienced in three attempts. Subsequent children were supposed to find their way into the world more easily than their elders, but not for us. Again, with number four, Maggie laboured throughout the night, with support from me and one of her close friends, Jenny. Malachy was delivered safely on the morning of 2nd March, with the attendance of experienced midwives and a local GP, who was a friend from the nearby town of Berry. The night's efforts left us all in a haze of exhaustion and excitement. After an initial check-over with doctor and midwife, Maggie and Malachy were transferred to the maternity ward of Nowra Community Hospital.

Not contemplating rest, nor hearing the rumble of the figurative freight train, I picked up the children from home where their cousin Lucy had babysat the long productive night. Bundled into the car, off to meet their new brother, were Imogen, in her Size 5 school uniform, three-and-a-half-year-old Seamus and Niamh, still herself a baby at 20 months. We all leapt out for an early morning hospital visit and our first photo opportunity with Malachy.

Niamh was ever so nervous as she climbed up into the low floral armchair, positioning herself to allow the brand-new bundle of brother to be balanced across her lap. Captured on film, her look is nonplussed. The strange living doll is warm and squirmy as Niamh lets her arms flop, unable to master nursing. In that first photo, Seamus has craned into view fascinated, delighted, his deeply tanned arms looping forward, where his index finger pokes delicately into the grasping palm of his newly minted playmate. Imogen, older and more competent, compliantly eager to please as she had always

It's a boy

been, mastered the cradling task after a brief hesitation. This boy was only a curiosity for now, but in time she would cradle, carry, comfort, capture and cajole him at every opportunity. The warm sleeping collection of swaddling left Imogen beaming at the camera, a euphoric wave of pleasure sweeping her along involuntarily. Love swept us all up in its blind intoxication.

Maggie went off to sleep while I went home, also planning to sleep. But adrenaline dictated that instead of sleep, I ring everyone I could think of to gloat about the safe arrival of our tallest baby, rivalling in beauty the earlier masterpieces. The thrill and satisfaction of completing our long-planned family buzzed through my weary brain as I finally succumbed, settling into a deep slumber.

Minutes later I woke to the urgent imperative of our home telephone.

While I'd been splashing our ecstatic news far and wide, Maggie fell into a recovery slumber. Malachy's crib was out at the nurses' station, ensuring peace and quiet for the new mum. It wasn't going so well for Malachy. Sister Helen had noted a dusky colour to the Frawley infant. A whiff of oxygen did little to improve his hue, and the oxygen level measured in his tiny fingertips registered an unexpectedly low score. While I was at home blithely crossing off one sibling then another from my list of calls, a drama was unfolding. Two doctors, an anaesthetist, Rob, and a paediatrician, Toby, had been summoned, drips inserted, and a set of X-rays ordered.

All the while Maggie slept.

Nothing the professionals did seemed to improve the appearance of this baby who had at first seemed a picture of perfection. In the unseen workings of newborn physiology, the oxygen that baby Malachy breathed had triggered a normal chain of events, transforming his circulation from that of a foetus to that of a neonate. While cocooned in Maggie's womb her lungs had given Malachy all the oxygen he needed, passing oxygen through the placenta with no need for the baby to breathe. Once he was delivered his own lungs and circulation would need to take over.

This brings us to the crux of the great 'What if'. That uncomfortable moment in the ultrasound suite had an explanation.

Malachy's heart had no valve opening to the lungs, hence no normal route to pump blood through the life-giving bellows. To get oxygen, Malachy relied instead on blood flow through the *ductus arteriosus*, a remnant of his foetal circulation. As the chemistry of newborn life worked its transforming magic minute by minute, Malachy's *ductus arteriosus* closed. This is normal. In a normal baby this closure makes the transition to healthy circulation complete, allowing the right ventricle of the heart to pump blood straight into the lung circulation. As Malachy's altered anatomy offered no other route into the lungs, an open *ductus arteriosus* was essential to his survival—its closure meant that Malachy's only way to oxygenate his body had disappeared.

With a violent hissing of brakes and steam billowing wildly as it crashed into the safety bollards, that freight train had arrived. If we had known what was coming, Malachy would not have been delivered in our small rural hospital, but in Sydney, straight into the waiting hands of intensive care experts. No delays and no surprises.

In my memory, the ringing of the phone that morning has taken on the screeching quality of an alarm. Shocked and stammering, I recognised the voice of the paediatrician on the line. 'Dom, it's Toby here. I've been called to look at your baby who the nursing staff observed to be cyanosed. He has central cyanosis, and his X-ray shows an enlarged heart. I think your baby has cyanotic heart disease, quite possibly Tetralogy of Fallot.¹

Minutes later, after a stricken car trip to the hospital, it fell to me to bring this news to Maggie. I tapped lightly and entered the peaceful shelter of the room. Maggie stirred, turning her face towards me, serenity and weariness in equal measure. 'Malachy is

1 Tetralogy of Fallot is the most common form of cyanotic congenital heart disease. The term 'tetralogy' refers to the presence of a combination of four different heart defects. The effect of the four defects is to produce low oxygenation, breathing distress, cyanosis of the skin and a 'boot-shaped' heart on Xray. Malachy had all those signs, but not the underlying Tetralogy.

It's a boy

at the nurse's station,' she murmured as she reached an arm out for an embrace. Warm as toast in her dream-like state, as Maggie touched my shoulder, she joined me at a point of no return.

'I know, darling, he's at the nurses' station, but he's not so well. There's something wrong. It looks like Malachy has a heart problem. Toby and Rob are both out there looking after him. They've called the helicopter. They have to send him to Sydney.'

The inner white noise of collision drowned everything.

The photos we had taken earlier that morning now carry the emotional weight of last capture—the last moments of normal life, a life which was soon to be divided into eras. As nature closed Malachy's *ductus arteriosus*, our life split in two.

Depicted are the last moments of 'Before'. Everything else is 'After'.

That day became a blur as events marched forward. I recall a flurry of discussion about the wind conditions and whether or not Maggie could join Malachy in the Care Flight helicopter to Sydney. I watched on helplessly as Maggie disappeared into the cramped cabin of the chopper, followed by Malachy, his ambulance trolley bearing him in the clear plastic shell of an emergency crib. The care of the other children needed sorting, with their cousin Lucy stepping in while I borrowed her car and drove alone through the dark, following the chopper.

The destination was Sydney Children's Hospital, where Malachy had all manner of drains and tubes pushed into his tiny body and was tested and retested to make a diagnosis. Maggie and I went through one detailed discussion after another and watched a range of staff dart in with various interventions to keep Malachy stable. We stared for hours at our unconscious baby, listened to the doctors and nurses, and stared at the walls of interview rooms.

3

INTENSE BEGINNINGS

If you are going through hell, keep going.

— Winston Churchill

On 3rd March I woke at first light. The struts of a fold-out bed had made their presence felt through the night. I creaked and strained my way into consciousness and breathed in the stale hospital air of Maggie's room at the Royal Hospital for Women. The main bed was empty. The emerging light of morning drew me to the window. I lurched suddenly. I choked, then sobbed. My body convulsed in waves as I realised where I was. I doubled over again as I realised why. Like a mute animal I leaked salt water from nose and eyes as stifled howls filled my chest. My tears would not stop, my eyes would not focus.

This must be what unbearable pain is like. Perhaps it's universal? Such suffering is lonely. The world came down to this one point in which I could not make sense of my altered state.

Is this my life now?

I sensed a presence. Turning to my right Maggie was standing still, fragile, her eyes reddened, watching with a veneer of calm.

'I wondered if you would have the same reaction as me,' she said gently.

Maggie had let me sleep, reasoning that I would need the rest after the distress of the preceding day. This was a pattern of caring that would sustain me in the trials ahead. I wanted, in turn, to be that same kind of rock for her.

Intense beginnings

By rights Malachy could have been called a ‘blue baby’, the traditional term for a baby whose heart could not deliver enough oxygen to his body. Oxygen turns blood pink. As it is used up, the blood and hence the baby, turns blue.

The lack of oxygen puts a blue baby at high risk of complications. Every cell in Malachy’s body was short of oxygen. His gut became susceptible to gangrene and infections. His liver strained to cope, leading to jaundice. While unconscious, the effects on his brain could not be known. Unable to mount a strong cough, his lungs clogged with secretions.

After four days Malachy wasn’t straight blue, but rather red, yellow and blue. His body, wracked with pain and arched in distress, was like a national flag for sick babies; a brightly contrasted line demarcating his red, infected abdomen from his yellow, jaundiced chest, while the tips of everything stayed obstinately blue.

Even after many years, the feel and smell, the air of disaster, still seem within touching distance. I can close my eyes and absorb once more the tension of not knowing, the powerlessness and the callous spotlessness of intensive care, with its soundtrack of beeps, blips and alarms. Still in my bones is the huddled gloom of the parents in the dreaded morning lockout while the doctors do their ward round. Each morning, hospital rules saw family members ejected from the Intensive Care Unit, to allow the doctors and nurses to speak freely about their critically sick patients. We were all forced out into a tiny anteroom with no facilities but a cramped row of chairs lining the walls.

I hope this dreaded cupboard off the main corridor at Sydney Children’s Hospital has changed in the years since, but in 1999 while the daily ward round was in progress, eight to 12 sleep-deprived, desperately worried parents had to share half a dozen chairs in a windowless corral, exchanging horror stories about their children while nursing their own fears behind a brave exterior.

It was often quite testing as the morning drew on and people's frustrations and worries about their children boiled over, without any capacity to seek redress.

Combing back through the memory of those early months of Malachy's life there is an image that forces itself forward, that crystallises what it felt like to be that parent, watching your beloved child struggle and suffer. Even now I shudder at the image I carry of my parched, toxic baby wracked by infection, fever, pain and dehydration. An organism barely conscious recognising only an instinct to live on.

Malachy's headline problem was his malformed heart. This vulnerable organ was responsible for delivery of oxygen to every other cell in his body. Nature's design would have us cry our way through our newborn period, plump and pink, our blood fully saturated with life-bringing oxygen to drop off at each needy organ in turn. When that doesn't work, those organs have to make do. If there is almost normal oxygen, your circulation works a bit harder, and you get by. With not quite enough, the struggle is more obvious, the system strains, the risks climb. Once you're clearly under-supplied, there is trouble, as we would discover.

Somewhere in the barrage of days that ushered Malachy into the world, as X-ray mounted on blood test and line after tube after drain were inserted and removed, Malachy developed a fever. Samples were taken to look for a culprit bacteria, as antibiotics were added on presumption of the likely organism, while he grew sicker. As the results arrived to advise a change was needed, that we won't win with these drugs, the tipping point was reached. His bowel, starved of oxygen and fighting off gangrene had started to die by degrees, signalled by a deepening red colour that lit the entire lower half of his body, stretching the skin shiny, brightly inflamed. Simultaneously the toxicity enveloped other functions as the fever rose, the struggling heart raced, and a deep yellow jaundice coloured his upper chest and back. Onto this red and yellow banner of human tissue came the gently probing hands of the surgical

Intense beginnings

registrar. The moment froze in time. Malachy arched in pain as the trained fingers sounded out the festering mess within. His mouth fell open, part agony, part air hunger, dry tongue and lips mutely crying for help.

This image lives on.

Enmeshed as I was in this battle for survival, I knew this life to be in the balance and that the path ahead would demand surgical intervention.

When the surgical verdict came down it carried the ominous name ‘necrotising enterocolitis’². As the seriousness of Malachy’s condition was explained the surgeon revealed the consensus view was that our boy was so unstable, so fragile, that the hospital would not risk transferring him down the corridor to the operating theatres. He was instead to be cut open right there in ICU. In the surgeon’s words, ‘If we don’t operate, he will die of this infection’.

So it passed that ‘Mac’, as he would be known, had his first operation when he was four days old. Not on his heart, but rather to remove a stretch of gangrenous bowel, a casualty of his hapless circulation.

On the day of Mac’s surgery, he became the reason all parents were herded out for prolonged exclusion from the Intensive Care Unit, which was now a sterile operating theatre. Long after the morning ward round was completed, our baby was still lying open on the operating table as the surgeons wrestled with diseased tissue to reclose the wounds they had inflicted. As tense as it may have been for all those parents, they did not force their pain on us. Perhaps it was our equivalent of battlefield solidarity—for we all found ourselves in this mess together. That day it was our turn to be that hapless family about which people can reflect, ‘No matter

2 Necrotising enterocolitis (NEC) is a devastating disease that affects mostly the intestine of sick babies, especially where there is a low oxygen level. The wall of the intestine is infected by bacteria, which can destroy the tissues, resulting in perforation of the bowel wall and life-threatening sepsis.

how bad it gets, in here you can always find someone whose child is worse off than yours'.

By the time the doors were opened, the news for us was that Malachy had lost a segment of bowel and still had extensive infection to combat. Malachy's bowel had been diverted to a 'stoma', an opening through the wall of his abdomen, where the bowel fed out through his skin into a colostomy bag.

Nonetheless, yes, he was alive.

4

SHUNTED

Eye contact: how souls catch fire.

— Yahia Lababidi

Day five dawned, and it wouldn't be accurate to say Malachy's recovery was uncomplicated. Certainly, the spreading gangrene of his bowel was arrested and the antibiotics were working their scientific magic, bringing the infection under control. Mac's vital signs were settling into a rhythm, but our baby still had blood tests and X-rays every day. Multiple tubes ran to and from his body, meeting his needs for breathing, treatment, nutrition, monitoring and excretion. He still had regular bouts of suction in which the nursing staff fed long plastic tubes down into his airways to suck out the messy secretions he was unable to cough up. He still had countless measures of every sign of life, every millilitre of urine, every dose of a plethora of drugs, every drop of fluid balance issued carefully and documented in detail.

All that careful watching was part of nursing him to recovery from his unplanned emergency operation. That procedure was marked on his body by wide rubbery-looking dressings that hid the incision line from one side of his abdomen to the other and by the colostomy bag, sealed to his skin to catch the produce from his shortened bowel. Malachy was yet to face his planned operation.

Feeding in through a large vein in Malachy's groin was what is known as a femoral central venous line. This is a specialised type

of 'drip', the more familiar type of needle often placed somewhere in an arm vein to feed a patient fluid and drugs. A femoral line is able to remain in place much longer than ordinary drips, is wide enough to have more than one 'lumen', or channel, and is fed into the largest vein in the body, the inferior vena cava, or IVC. The IVC is big enough to allow noxious chemicals to be fed into the bloodstream without as much risk as usual of corroding the vessel. Malachy's tiny femoral vein was just large enough to accommodate the insertion of the femoral line.

One of the drugs being fed in through Malachy's groin was Prostaglandin. This wonder drug, fairly recently developed, was keeping Malachy alive by holding open his *ductus arteriosus*. Without this drug, the ductus would close, plunging Malachy back into the type of crisis we had witnessed on day one at our local hospital. As days passed the risk increased that nature would override the effect of the Prostaglandin, so it became imperative to avoid undue delay of an operation for his heart.

Gary Sholler, the cardiologist, and the cardiac surgeon, Graham Nunn, advised us that Mac needed a procedure to create an artificial blood vessel or 'shunt' to divert blood from his body into his lung circulation. On its return to the heart from the lungs, this blood would then mix with the blood returning from the body, to make partially oxygenated blood, to send back out around the body. The doctors emphasised this would not be perfect as normal hearts have two pumping chambers, or ventricles, for a reason. But Malachy's anatomy was so malformed that functional, not perfect, was the goal.

All the while Malachy was kept sedated, buried in his struggle for survival with painkillers and sedatives added to the more technical aspects of his treatment. He couldn't be detached from the life-preserving apparatus surrounding him so remained impossible to hold or hug. His eyes remained steadfastly closed.

A narrow window of time beckoned. Malachy needed to be adequately recovered from his bowel surgery to handle having his

Shunted

chest cut open, but he couldn't wait too long because his *ductus arteriosus* would close, spelling disaster.

Our other children came and went, in the temporary care of rallied family and friends. Visitors came and went too, each contributing something special of their own to a wave of goodwill sweeping us along. The daily rhythm of tests and discussions, ward-round lockouts, and arrivals and departures of yet more sick babies and distraught parents rolled on. The ambience of neon lighting was relentless, as day was hardly distinguished from night. The to and fro along barren hallways to meet our needs for sleep or sustenance, or to express breast milk, then back to care for our stricken baby, seemed endless.

Through all of this, something started to niggle at Maggie and me. After more than a week, Malachy had never voluntarily opened his eyes. Nurses had prised open his eyelids to force the glare of torchlight through. Presumably, this was to confirm the presence of brain function. There had been no visual bonding; no loving stares between parent and child were given or received. A maze of tubes and cords made cuddles a no-go, leaving stroking small available patches of skin about as good as it got. What meaning we attach to our eyes! Can you really pour love into a child through this bejewelled portal? It dragged on; our baby couldn't see us at all, and we had no window to his soul.

One morning early, a gift lay on the table at the base of Malachy's crib. One of those special people, able to bring a light heart to a hard place, had nursed our boy through the neon harshness of another night. A pile of Polaroid photos taken through the night bore the title: *What Does Malachy Do When His Parents Are Asleep?*

We paged through a series of stop-motion photos with some soft toys assembling on Malachy's bed, and a Pelican daring to venture closer, closer, to the head of the human. The pelican appears to whisper in Mac's ear. What was said will remain between the two of them but what we saw on the final page was unmistakable. A strip of deep blue-black colour had opened up below the brow, as

the toy pelican leaned in for a response. There seemed no doubt that here in truth was an open eye, for the first time, witnessed by Mr Pelican.

The next day, with Malachy around ten days old, the surgeon got the green light to proceed with the shunting operation, opening a wound running between two of Malachy's ribs, wrapping around the left-hand side of his back. With Mac's ribs held open by his surgical assistants, Graham successfully manipulated the minute vessels to achieve the desired outcome, ensuring safe blood flow into Malachy's lungs. The procedure he performed was the installation of a Blalock-Taussig shunt. This was an operation conceived in 1943 and given some degree of fame as a focal point in the 2004 movie *Something the Lord Made*. The movie depicts the development of the shunting procedure through the bravery and genius of three people in the US: a laboratory technician named Vivien Thomas, with the surgeon Alfred Blalock and cardiologist Helen Taussig. Their reach into the future had that day saved Malachy's life.

After such an arduous and complex period of suspense, each day was happier than the one before as Malachy first pulled through the operation, then was progressively relieved of one tube or catheter after another. Gradually he needed fewer drugs and less monitoring. As the treatment eased off, the sedation lightened.

When he was two weeks old, Malachy opened his eyes and stared at his parents, obviously unaware of the profound effect this novel action had on them. His eyes had the expected deep, baby blue colour, which would in time be replaced by the brown he inherited from me.

On day 15, with Malachy more alert, and with one less line attached to his tiny body, Maggie was allowed a moment she had been craving. A chair was positioned next to the crib, and the drip stands all moved beside the chair. Maggie was guided to the chair. The plastic tubing was freed of tangles and a pillow placed on her lap. Onto that pillow Malachy was placed. There, mother

Shunted

and son would enjoy their first embrace since the chain of disaster was set in motion. We have a photo of that moment when Mac could first receive a physical demonstration of love, of something other than a medical or surgical salvage procedure. Maggie is looking upward into the camera with an uncertain air born of the preceding trauma, mixed with relief. The blue of her eyes is striking next to the lingering rings of redness. Layers of meaning seem to stare through the camera as, cradled afloat on a pillow is a tiny, blue-pink bundle, string-like tubes trailing off towards the adjacent drip stand. I felt overwhelmed with tenderness for both of them, the woman who had steadfastly endured every drama, all the while unable to hold or caress her featherweight child, and the boy who, in his battle, had carved himself so deeply into my psyche.

By the time Malachy was laid out on his mother's lap, Maggie and I felt as though we'd been through a lifetime of sombre discussions, of sleepless nights, of consoling distressed relatives and bolstering each other. Malachy's life had hung by a thread from hour to hour, day to day, and we had grown accustomed to the intensity of watching for every movement, every change, any sign that the balance had tipped either for or against this tiny suffering creature.

The bond of love for a child is so rarely tested to this degree. Under this kind of duress you are forced to realise with great clarity just how much you love them. It created a profound distillation of the essence of parental love; That a human being I hardly knew, who had never spoken a word to me, could move me so powerfully. One friend of mine suggested that babies like Malachy, or threats to the life of any one of your children, 'Make you want to hug them harder'.

Basking in the joy of being able to cradle and nurture our boy and to finally share a mutual gaze, we made little of various complications. Among these was some minor damage to Malachy's femoral artery, the major vessel supplying blood to his right leg.

It was also found that the femoral line, so essential to delivering treatment to the infant, having fitted so snugly in the blood vessel, had caused a clot to form, completely blocking the major vein to the heart, the inferior vena cava.

This blockage would prove to be another 'What if?' as events unfolded.