

Twins **Daniel** and **Joshua Turner**, who were born at 24 weeks, touched by mother Linda Hall in the neonatal intensive care unit of the Mercy Hospital for Women three months after they were born.

Joshua Naua's life has just begun – unexpectedly and traumatically. Love had set him ticking in his mother's womb but now he is being nurtured by cold, hard science, lying in a plastic crib under a layer of bubble wrap. The bleep of a ventilator has replaced the dull thud of a maternal heartbeat.

At just 24 weeks and five days, the newborn is already a centenarian tottering on the brink of old age, exhausted, shrunken and bald; more fetus than baby. His skin is so fragile it leaks, his eyes a mystery, fused shut against a world of which he is not yet ready to be a part. Smaller than his father's footprint and weighing just less than half a kilo, he is lost in a city of machinery, a jungle of wires. They run from his nose, his belly button, his feet, feeding him oxygen to help him live and morphine for the pain that life brings.

Joshua has a twin brother, Lachlan, who is fighting a similar battle in a different hospital. Born within a minute of each other, they are now separated by 25 kilometres of suburban prairie, victims not only of premature birth but of an overloaded health system. Their parents, Lisa Hawkesworth-Naua and Asaeli Naua, stand by Joshua's cot, lit up like a space capsule, their faces expressionless. When pain permeates the numbness, they look away.

Up until yesterday, they had led a relatively ordinary life, untrammelled by the big existential questions of life and death. They went to work, played sport, made dinner, read the papers – only a few days ago, Lisa had seen something about a bed crisis in Victoria's neonatal intensive care units but hadn't given it much thought. She was breezing through her pregnancy; apart from being tired, there was nothing to suggest anything could go wrong.

On a hot Wednesday evening in mid-January, she felt a niggling pain. At midnight, it woke her up and by 1am she knew she was in labour. An ambulance bore her to her local hospital in Frankston – she was too far gone to head anywhere else. And then just before dawn cracked like an egg over the city skyline, her twins slipped from her body and her grasp. The hours that followed were blurred by shock; she remembers them lying on her chest seconds before gloved hands swiftly removed them, their kitten cries floating across the room, messages to which she could not respond.

Lachlan, the bigger of the two at 625 grams, was taken to the neonatal intensive care unit (NICU) at Monash but there was no room for both babies. Lisa, born and raised in the south-eastern suburbs, had no idea where the Mercy Hospital for Women was, or even Heidelberg for that matter, where, on the second floor of a tall white building, the NICU team is getting ready for another busy day.

There are 31-week-old triplets due to be delivered as well as a 24-weeker who is on his way and will need to be fitted into a ward already bursting at the seams. "What are we supposed to do? Open the car park?" mutters a nurse, shaking her head. "Bunk beds?" suggests another sardonically.

Black humour is a godsend when you work in a dark place. NICU has its fair share of miracles but at times it is filled with inexorable heartache. In three rooms, there are 28 beds filled with the tiniest of forms. The word *preemie* conjures up images of cuteness – miniature infants, half-doll half-baby with big eyes and tiny pink hands – but it doesn't capture the reality of children such as Joshua, the colour of a bruised plum, whose heart flutters delicate as a butterfly wing

amid the restrained hustle. On NICU wards, a day can mean the difference between life and death. Babies born before 23 weeks are rarely considered compatible with life, between 23 and 24 their chances of survival are slim (see table on page 43).

Joshua's chances are even lower at birth owing to his small size, so Lisa is told, but if he can make it through the first three days, the odds will improve significantly. Fifty per cent of babies born at his age get to go home, though up to 20 per cent will be severely disabled; the rest will be either fine or affected by conditions such as milder forms of intellectual delay and cerebral palsy. Girls do better than boys, for reasons that are not clear.

Already, Joshua is doing better than his brother, Lachlan, who has suffered a bleed on the brain, one of the common problems of extreme prematurity. Lisa and Asaeli have been warned that this could lead to profound disability, but this is hard to take in. Lisa is pragmatic: "We will cross that bridge when we come to it." For now, all they can do is wait, flitting between the two hospitals in three-hour round trips, trying to grow their babies, who cannot yet metabolise milk, with love instead. They have already learned the first lesson of parenting; that it can be as difficult to leave your children as it is to stay with them.

On the ward at the Mercy, associate unit manager Estherie Tung is bustling from room to room, brow furrowed, clutching a clipboard. In the twilight interior, it becomes apparent that just about every piece of equipment is on wheels because nothing here is still for long; not people, not babies, not time. She is still trying to find space for the expected triplets to be

delivered that afternoon, but it is not known what level of ventilation they will need. Hopefully, they won't be split up. Victoria's four neonatal intensive care units are all full; if one of the babies requires specialist equipment, they don't have going spare and it may mean a trip to Adelaide, Canberra or Sydney.

Earlier in the week, premature twins born in Shepparton were flown to South Australia because there was no room in Victoria. "My job involves a lot of lateral thinking," says Tung, poring over her clipboard, trying to work out which of the babies currently residing in the unit, if any, can be downgraded to the high-dependency ward and allowed to draw breath on its own.

Over the years, Tung has seen the number of admissions multiply. She jokes about the baby bonus, but it has to be more complex than that. Women are giving birth later in life. IVF has led to an increase in twins and triplets, who are more likely to be born preterm. Fifty per cent of women giving birth these days are overweight, which in turn leads to other complications such as high blood pressure, pre-eclampsia and gestational diabetes. What Tung knows for sure is that the pressure the nurses are under is enormous. The burnout rate among staff is huge. Ninety per cent of NICU nurses work part-time, partly because many are mothers themselves but also because living amidst the drama of life and death on a daily basis takes its toll.

The cry for more beds is a refrain that's been growing in volume for years. The Mercy has 19 NICU cots with a flex capacity of 21, meaning that in a crisis

THE EDGE OF LIFE



At Melbourne's Mercy Hospital, every day makes a difference for the babies born extremely prematurely. Kathy Evans reports from the neonatal intensive care unit.



Photography:
Penny Stephens

The Turners
Daniel Turner, right,
and Joshua, below,
born at just over
24 weeks.



Right Daniel Turner holds his mother's finger.



Right Joshua Turner, Daniel's twin.



Far right Linda Hall feeds her son Daniel, who has grown out of the "one-kilogram club" to weigh 2.5 kilograms here.

suddenly, brought on by a kidney infection. Linda had woken up on a Sunday morning in late November feeling a bit under the weather but had carried on with the routine of the day, swimming with her two-year-old and doing the shopping before getting her mum to take her to her local hospital in the evening "just for a check". Her silent fears were confirmed; she was in labour. Soon, an ambulance was whizzing through the darkening streets at breakneck speed towards the Mercy. She remembers the paramedic jokingly telling her to smile as they tore past speed cameras.

At first, it was touch-and-go for both twins. Joshua spent almost a month hooked up to a life support. "We just take it day by day," says Linda with a calmness that you'd imagine masks an internal maelstrom. Still, motherhood is one of those things that some manage so naturally they give the impression of never having to think about it. Linda gently strokes the wizened, furrowed brow of her tiny son with one finger, smoothing, murmuring till the baby melts and softens. It is getting easier.

When she first held him, three weeks into life, the procedure was as complicated as a prison visit. The cumbersome life-support machine had to be navigated, the tubes, the wires, the temperature monitored, the moment, so private and tender, observed by hovering medics for signs of stress. And she was nervous about touching something so vulnerable it could vanish.

Four years ago, Linda gave birth to a daughter, Chloe, at 23 weeks, after her cervix sprang open unexpectedly. The baby lived just minutes. And so she has learned that love must be guarded, it is too dangerous to feel when it dances this close to death. Before Chloe's birth, she bought nappies in readiness. This time, she has bought nothing. Back at their home in Pakenham, her husband, Robert, a shop fitter, wants to look at prams, but all that can wait until she knows her sons are coming home.

it can take additional babies for a short space of time – hours, rather than days. Last year, each of Melbourne's NICUs was found to be operating above its normal capacity 50 per cent of the time. Today at the Mercy, there are 23 babies crammed onto the ward; it is hard to say no when a desperately ill infant has nowhere to go. NICU director Andrew Watkins likens it to a game of chicken – which hospital will crack first.

Watkins spends a large chunk of his time trying to alleviate bed crises. But figures don't paint the picture of what happens when overcrowding occurs. It means stressed-out staff begin to call in sick, nurses and doctors work double shifts in a fug of tiredness and the risk of infection goes up. The knock-on effects can prove lethal in areas least expected; often, it is the baby in special care who has turned a corner and is doing well who suddenly goes downhill as a result.

"Overcrowding means the burden of care for the baby goes up," says Watkins. "We cope with a crisis, but it is a delusional form of coping. Unfortunately, this is normal, and it's dangerous."

There is no pleasure in the irony that the NICU is

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a victim of its own success; 20 years ago, 28 weeks was the limit of viability for premature babies. Today, sophisticated advances in biomedical engineering, with cots that light up like cockpits and drugs such as surfactant derived from animal lungs – a miracle elixir that arrived in the early '90s and drastically reduced the amount of lung damage – have gone a long way in mitigating some of the critical effects of extreme prematurity. As well as surfactant, the '90s saw the arrival of other non-invasive respiratory supports such as continuous positive airways pressure (CPAP), administered via a set of nasal prongs that keep the lungs inflated like mini-balloons. It is a pattern of management that is gentler for the baby than the older-style ventilators but is even more dependent on nursing care – hence a ratio on the NICU ward of one-to-one. The result is that younger-than-ever babies are now surviving ... and needing beds for longer.

Linda Hall is about to cuddle with her son, coincidentally also named Joshua, six weeks after giving birth to him and his twin, Daniel, at a shade over 24 weeks. Joshua, the smaller of the two, weighed 640 grams, his brother a little more. As with Lisa Hawkesworth-Naua, labour announced itself

Right Lisa and Asaeli watch over their son, Joshua, in his humidicrib at the Mercy Hospital in Heidelberg three weeks after he was born. Joshua's twin brother, Lachlan, didn't survive.



The Hawkesworth-Nauas
Lisa and Asaeli and baby Joshua, three weeks after he was born at 24 weeks and five days.

Linda speaks the language of a medic – like a tourist in a strange land, it's easier if you adopt the local lingo. In their line of work, Lisa and Asaeli have never had to think very often about sodium, chloride and potassium levels or strange-sounding words such as bilirubin and cyanosis. Nothing about their jobs requires them to be the least bit knowledgeable about the biochemical processes that go into inflating a set of lungs. Within 48 hours of their sons' births, they too are becoming fluent in this foreign tongue where innocuous acronyms mask a riot of emotion – "ET" for an endotracheal tube (a piece of hose pipe inserted through Joshua's tiny nose and into the trachea that connects to a ventilator) or "NG", shorthand for nasogastric tube; part and parcel of life when you weigh less than a bag of sugar. This is raw motherhood, stripped of its fantasy of frilly bassinets, designer clothing and soft furnishings – that cheerfully constructed bauble crushed easily as an eggshell.

On a long night shift, when the ward is dark and largely quiet, punctuated by the rhythmic beeps of machines and the quiet movement of nurses, Andrew Watkins talks of life in a grey zone, where no decision is ever simple. Doctors cannot accurately predict at birth which babies will survive and do well, or which ones will have disabilities. "We can quote odds that are well researched and mostly right, but parents don't want to know what is going to happen to a percentage of babies, they want to know what is going to happen to their baby, which is just what we can't tell them."

When Watkins, now in his 50s, trained as a doctor, the teaching of ethics meant little more than not sleeping with your patients or poaching anyone else's. But on the NICU ward, there are a lot of hard knots to unravel. Babies are being born on the cusp of the age when fetuses are aborted. While neonatologists are battling to save the life of a 24-weeker who

"The test I apply is whether this is a decision that a loving parent would lovingly make."

Andrew Watkins

Right Asaeli Naua holds Joshua's beanie.

Far right Lisa Hawkesworth-Naua changes Joshua's nappy.



could well be prone to a life of disability, in a clinic not too far away another life will be terminated, possibly for similar reasons.

It's just one of the quandaries thrown up by a treatment still in its infancy. Here's another: Australia has a poor track record in providing good-quality care for people with disabilities. Is it ethical to bring children into a world that offers so little in terms of support? Watkins makes a point of telling parents they are going to have to become tougher people than they ever thought possible, fighting to get justice for their child. He is the first to admit that the technical abilities of his profession can lead to dilemmas. Mostly, moral conundrums can be worked through, slowly, painfully, with the parents.

Watkins draws on his own experience as a father of three to guide him through the maze: "The test I apply is whether this is a decision that a loving parent would lovingly make." If you come from the standpoint that you all want what's best for the child, it puts you on the same playing field. But there are occasions when this doesn't happen, when parents want their child to be resuscitated even though its chances are nil. Watkins talks about giving infants a "trial of life", which most parents agree to; if at the end of it, there

is still a disparity between the medics and the parents "then you have to do a lot more listening and a lot more talking". While parents are legally responsible for their child, they cannot demand treatments that are deemed futile. Most neonatologists, at some point in their career, will come across parents who demand their baby be "switched off" if there is any risk of disability, and others who push for treatments for their extremely sick infant long after the treatments have ceased to be worthwhile.

Sometimes the decisions made, with hindsight, are wrong. Doctors have baggage about death and disability which is not always consciously recognised and which can affect their judgement of what makes a good life; intellectual disability for some, is quite literally considered a fate worse than death. On the other hand, egos push boundaries to produce "miracle babies" which are not going to be raised by super-parents, only ordinary ones with limited resources.

Staff learn to live with moral distress. For support, they turn to each other, their families, on-site counselling, regular debriefing sessions, the pub. Watkins, an atheist, and the rest of team, a

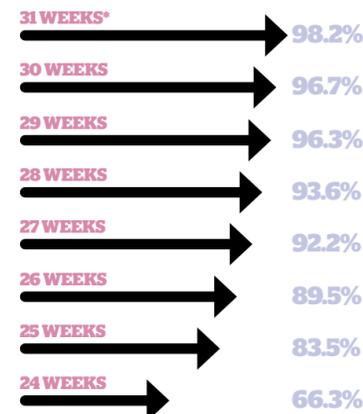
heterogeneous group, draw support from the hospital's ethicist, Father Cormac Nagle, a Franciscan priest who has dedicated much of his life to trying to find answers to seemingly intractable complexities such as these. According to the Catholic tradition, doctors are bound to take "ordinary or reasonable proportionate care" but not "extraordinary or disproportionate means" to keep someone alive. Two factors are balanced in deciding what is ordinary: the burden placed on the baby, its parents and the health-care system versus the benefits received by all three.

Yes, it's like playing God, which is why Nagle argues that, when in doubt, it is always better to err on the side of doing something rather than nothing. Sometimes things go wrong: "You can't blame yourself. You can only do what you can in the moment when you make your decision; otherwise you can go crazy, worrying about the decisions of the past." Or, as Watkins puts it, "The only way never to be wrong is to never make a decision. If you have never done things you think are morally wrong then you are probably not paying attention. In the grey zone, no one knows what is right."

On a Tuesday morning, doctors call Lisa and Asaeli into Monash and gently explain that Lachlan, barely a week into his life, is not going to get any better. The bleed on his brain has done irreversible damage. Although his lungs are improving, his long-term prospects are not; a lifetime of blindness, deafness, cerebral palsy and severe brain damage lies ahead.

Who would want that for their child? There is a difference between living and existing. Lisa and Asaeli attempt the impossible, imagining a future where Joshua is playing rugby and Lachlan, unable to see or walk, let alone kick a ball, cannot join in. In their mind's eye, Joshua is burdened by a silent lifelong guilt, they themselves are fraying at the seams, time is

Survival rates of babies born early and placed in intensive care in Australia and NZ



*Gestational age. Note: most babies born at under 24 weeks will die on delivery. Some robust babies will go to intensive care; if they live, many will have long-term disabilities. Figures: Australian and New Zealand Neonatal Network 2007.

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stolen from one son for the overwhelming needs of another. There would be no more children. Lisa, a manager of a shoe shop, would have to give up work. They wander around the corridors of the hospital feeling defenceless against the rising tide of a future that just won't go away.

And so they learn another lesson of parenting; how hard it is to let go. Lachlan is unhooked from tubes and wires that had kept him alive and is taken into a private room. He lives for an hour-and-a-half before taking his last breath in his father's arms. Afterwards, Asaeli bathes him.

Lachlan never opened his eyes, never saw his own image reflected in those of his parents. It will, however, live on in the shape of his identical twin, a lifelong bitter-sweet reminder of what could have been.

When a child dies, there must be someone to blame because the sadness is just too big for one pair of arms. Grief is so dreary and demobilising; how much easier if it undergoes some sort of internal alchemy and emerges as white hot, invigorating anger. When Codi King died after almost nine months in NICU, his father, Jarrod, projected his fury onto a faceless, invisible god. "I can't wait to meet him," he says tersely. "I have a couple of nice words for him." Codi's mother, Kellie, blamed herself. Why not, when the literature of pregnancy bristles with threats of reprisals if you step out of line. Not that she ever did, but still, "I asked myself, did I wear my pants too tight, did I eat something?"

Codi was born 24 weeks and one day into a pregnancy pockmarked by unexplained bleeding. It was grand final day; St Kilda and Collingwood were heading for an historic draw when he slipped into the world and was swaddled in bubble wrap to keep him warm. As the room filled with doctors, his frail cry balled in Kellie's stomach. Never had she felt so useless, marooned from her child by a gaggle of medics and machines, unable to comfort him. "I felt sick, I couldn't watch."

It was two months before she got to hold him, his skin delicate as a skein of silk that could rip at her touch. He was going for his first operation to seal a duct near his heart that hadn't closed with his first breath. He survived that operation, and others; including one to repair his throat damaged by the tube of the ventilator. He was transferred to the Royal Children's Hospital and then back to the Mercy

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