



*Not Compatible
with Life*

a diary of keeping Daniel

Kylie Sheffield

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For Daniel, my beautiful boy.

*For all the amazing mums from
LivingWithTrisomy13.org.
You and all your little ones,
living here
on earth and elsewhere,
are an inspiration.*

And for Paul and Gabe.

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Author's Note

This book is a labour of love. I offer it to you asking only that you take it with an open mind and an open heart.

It is not my intention to criticise, in any way, the decisions or actions of *any* parent who has received a difficult prenatal diagnosis. It *is* my intention to accurately describe the circumstances and choices confronting these parents, and to help others to realise that our babies, too, are precious and longed for.

Not Compatible with Life: a diary of keeping Daniel is distributed as a pass-it-on book in the hope that people everywhere will have the opportunity to read Daniel's story. Increased awareness and deeper understanding is the greatest payment I could receive.

Kylie Sheffield

October 2007

If you would like to own a copy, or to contact the author, please email: danielsbook@aapt.net.au.

Disclaimer

Not Compatible with Life: a diary of keeping Daniel is expressed from the author's perspective, and is not intended as a substitute for accurate medical advice or skilled counselling.

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Chapter 1

First signs

Monday, March 5

The sonographer arrives bang on one. His name is Trevor. He escorts me into the dimly lit room, makes me comfortable, offers polite chitchat. He will have a good look at my baby first, he says, and then explain what he is seeing. The whole procedure should take no more than fifteen minutes.

When do I first suspect that something is wrong? Maybe it's when I notice the digital clock on the wall tick over 1.45, or when I see the same perspective of my baby's skull appear on the screen for the seventh or eighth time. I feel like an oversized mouse pad as the scanner glides left and right across my gelled-up belly, and dread curls its way through my gut, killing the flutters of excitement.

At last Trevor speaks. He is having problems getting some of the angles he needs, so continues to poke here and prod there for a further fifteen minutes. I stare at the screen above me, trying to make sense of what I am seeing, looking for clues, to what I don't know. I catch glimpses of my baby's spine, a foot, a face, and the gently throbbing lump that can only be the heart.

Finally it stops. Trevor is seeing some things that don't look quite right. He needs to be sure. Can I sit tight, jam-packed bladder and all, while he seeks a second opinion? I stare at the now blank screen and do the only thing I can: whisper over and over, 'please God, let my baby be okay.'

Enter Tim, radiologist. Again my baby's skull bobbing before me. Nods. Clucks of the tongue. Anatomical terms exchanged in hushed tones. Now the heart, now the kidneys, now the tiny profile. Exit Tim to page the consulting obstetrician while Trevor sits down and again wields the scanner, this time verbalising my fears even before my mind has allowed me to acknowledge them. My baby's skull is strawberry-shaped, there's an absence at the back of the brain, the kidneys appear to be too prominent, there's some disproportion in the chambers of the heart and a possibly receding jaw structure. Bottom line: these are 'markers' commonly indicative of a

chromosomal disorder. Is it Down syndrome? No, the chromosomal disorders we're talking now generally have far graver outcomes. I'm sorry, I stammer, I'm not sure what that means. Well, Trevor says gently, these disorders are 'not compatible with life'—the baby will most likely die in-utero or very shortly after birth. Many people whose babies are diagnosed with these conditions choose to end the pregnancy.

Bam.

Head and heart racing, I ask how much longer this will take. I haven't made arrangements for Gabe to be picked up from school, I was sure I'd be back in time. The consultant arrives and gives me time to sort it. Her name is Helena Johnson. I wriggle to relieve the pressure on my bladder and try to articulate the questions piling up behind the growing lump in my throat. Helena is patient. She doesn't mind when I repeat myself. She doesn't make me feel stupid or ignorant. She doesn't call my baby 'it' or speak as though there's not another life inside me. She tells me I'm carrying a little boy. She asks me to come back tomorrow for a second scan and suggests that I consider amniocentesis. Finally, as she hands me a towel to mop the gel from my belly, she asks if I'll be okay. Of course, I say, I'm fine.

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Autopilot kicks in as I drive the twenty minutes to pick up Gabe from my friend's house. When I arrive, the first wave of grief hits. Danyelle does everything right. She listens, she hugs me, she cries, she holds my hand and tells me to call her if I need anything, no matter what time. I know she means it.

Home again, home again, I say to Gabe as we drive away. Jiggety jig, he says back and I put on my sunglasses so he won't see me cry. I've picked a name, I tell him. It's Daniel Sean—do you like it? I love it, says Gabe. So it's decided.

Walk the dog, homework, dinner. Everything is normal. Everything is fine. I phone my husband Paul, who's interstate. He books the first flight home. I phone my family in Queensland. More questions. More tears. Bath, story, bed. Finally I'm alone with my baby. I feel him moving inside me and know all I can do is wait. And pray. I lie beside my slumbering six-year-old and stroke his hair. When, an hour later, sleep still eludes me, I slide from the bed, tiptoe to the spare room and turn on the computer.

Fear played no part in the first nineteen weeks of my second pregnancy. When Daniel was conceived I was fit and feeling great—I had recently trained for and competed in a half-marathon,

my diet was largely organic, and I had taken all the recommended pre-pregnancy supplements—so from the moment I saw the second thin blue line on my home pregnancy test, I was confident I would deliver a healthy baby come July the following year.

When at almost fourteen weeks I was offered maternal serum screening (MSS) I declined, largely because I understood that it could not produce a definitive result. The purpose of MSS is to identify babies at higher risk of Down syndrome, anencephaly and spina bifida¹, but it cannot confirm or rule out the presence of these congenital problems. Instead it returns an ‘estimation of risk’ and, if this is greater than 1-in-250, further screening is offered, usually in the form of a nuchal translucency scan.

As both MSS and nuchal translucency return a percentage of ‘false positives’ and ‘false negatives’, some babies assessed to be at higher risk will turn out not to be affected, while others deemed to be low risk will be born with the targeted congenital abnormalities. It was too late in my pregnancy for nuchal

1 Anencephaly and spina bifida are neural tube defects. In the case of anencephaly the brain is very underdeveloped, while spina bifida involves a malformed and exposed spinal cord and possible lower body paralysis.

translucency to deliver accurate results so, for me, the next step would be amniocentesis, an invasive diagnostic test carrying a 1-in-200 risk of miscarriage.

At thirty-seven, my risk for Down syndrome was already 1-in-242, but I was not convinced it would benefit me to know of such an outcome in advance. Paul and I felt strongly that we would be able to accept and love our baby irrespective of any disability. We saw no point in undergoing early testing which would not alter the outcome of my pregnancy, regardless of what it revealed. For these same reasons I initially considered foregoing the recommended prenatal ultrasound at nineteen weeks. Ultimately and, as it turned out, somewhat ironically, I consented to proceed for peace of mind. I had planned to give birth at home and an ultrasound, I thought at the time, would rule out some of the more obvious problems that might hinder a safe home delivery. I had never heard of ultrasound markers, and did not understand what they might mean. I certainly knew nothing of the myriad of congenital disorders to which I would soon be suddenly and shockingly introduced.

Prenatal ultrasound has become such an established and widely sanctioned facet of the contemporary woman's pregnancy

that the vast majority of mothers-to-be undergo at least one and, more commonly, multiple scans. But how many of us, as we dutifully report at the twelve- or eighteen-week mark or eagerly request more regular glimpses of what lies beneath, appreciate the capabilities, limitations and risks of this technology we have so readily accepted as a fundamental part of the antenatal experience? How many mothers-to-be, as they lie, bulging bellies exposed, staring wide-eyed at the fuzzy pictures before them, are really aware of what those images might reveal or, as importantly, what they might not?

According to Monica Rafie, founder of BeNotAfraid.net, a support web site for families receiving a poor prenatal diagnosis, many women are reluctant to undergo prenatal screening, but assume that the benefits of proceeding will outweigh their reservations. ‘They are not always informed,’ she suggests, ‘that from a medical perspective, the primary purpose of this prenatal screening has less to do with improving or ensuring [the] health of the baby, and more to do with identifying babies at higher risk of syndromes or congenital malformations as early as possible.’¹

Internationally published advocate for gentle birth, Dr Sarah Buckley, shares Rafie’s concerns.

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... [women's] experiences and wishes are presumed to coincide with, or be less important than, the medical information that ultrasound provides. For example, supporters of RPU [routine prenatal ultrasound] presume that early diagnosis ... is beneficial to the affected woman and her family. However the discovery of a major abnormality on RPU can lead to very difficult decision-making. Some women who agree to have an ultrasound are unaware that they may get information about their baby that they do not want, as they would not contemplate a termination.²

When I agreed to a routine scan, I was concerned only with ensuring that my baby was as fit as any other to be delivered at home. I don't know that I had ever heard the procedure referred to as a 'foetal anomaly scan', pondered the fact that its primary purpose was to screen for and detect specific abnormalities that may indicate the presence of serious congenital defects, or considered that it was timed specifically to allow parents the option of terminating before the twenty-fourth week of the pregnancy.

In hindsight, it seems unbelievable that I could have been so naïve, but the results of recent research confirm that I was not alone. In a study of women attending public antenatal clinics at the Royal Women's Hospital between January 2003 and December 2004, researchers conclude that many Australian women participating in prenatal genetic screening are not well-informed, particularly regarding the potential need for follow-up diagnostic testing and the risks that come with it.³

A separate study of women attending specialist ultrasound practices for first-trimester screening for Down syndrome returned similar findings—of the 163 women who participated, only 68% were assessed to have made an informed choice. This suggests that even in private clinical care, Australasian Guidelines on prenatal screening—which state that all women undergoing testing should be provided with written and oral explanations, and that proper understanding of the tests should be ensured—are not being met.⁴

On the day of my own scan I was filled only with a sense of eager anticipation, and was completely clueless as to how ill-prepared I was to deal with any negative prognosis. When, after an hour of prodding and probing, the sonographer's words

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came at me like bullets, the only ones that really hit home were ‘not compatible with life.’ Even after the consulting obstetrician’s explanation, though thorough and sensitively delivered, I found myself unable to grasp the facts. I had felt this baby moving inside me for a number of weeks now, and had just observed his antics on screen for more than an hour as he kicked and squirmed and sucked his thumb. Surely it wasn’t possible for him to be anything but healthy?

Disbelief and denial, I’m told, are common reactions among expectant parents whose scans reveal serious problems. This is hardly surprising when so few of those who submit to foetal anomaly scanning are aware of the common markers and their significance, or prepared to receive anything but good news.

The night I spent alone after Daniel’s markers were first detected was the most anxious of my life. And while nothing could have prepared me for the shock of discovering that my baby’s life might be at risk, I could certainly have pre-armed myself with a more thorough knowledge of ultrasound, and the diagnostic procedures I may subsequently be offered. At least then I might have spared myself the bewilderment that accompanied my grief. As it was, I felt I had been blindsided. So I found myself trawling

the internet sometime after midnight, hoping to draw a coherent conclusion from jumbled recollections of what I had been told that afternoon.

Ultrasound markers, I discovered, are deviations from the normal anatomy seen on an ultrasound scan, and can be one of two types: significant structural problems, or minor and often temporary structural differences called ‘soft markers.’⁵ Conditions such as anencephaly, where the brain is very underdeveloped, are obvious structural problems and therefore easily detected. The identification of soft markers can be far less straightforward. Some common examples are *echogenic intracardiac foci*, which appear as white, golf ball-like features on the heart; *choroid plexus cysts*, seen as black spots in the brain indicating fluid collection; and *echogenic (or echo reflective) bowels*, where the bowels appear bright on ultrasound. In isolation, these and other soft markers are often of no significance, and can appear in perfectly healthy babies. Occasionally though, and especially if multiple markers are found, their presence may indicate an underlying chromosomal abnormality.

My initial scan revealed five markers: a strawberry-shaped skull, an absence in the brain, a possibly receding jaw, echogenic

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(or bright) kidneys, and a small left heart. While I knew that Daniel's condition could not be properly diagnosed based on these indications alone, the presence of multiple markers certainly suggested that the likelihood of him being completely healthy was extremely low. Following links and visiting chat rooms, I found no shortage of anecdotes from women whose babies were born healthy despite the detection of one or even two common markers. But none of those babies had five. Five, web site after web site and article after article cautioned, equated more often than not to a chromosomal syndrome. I had no idea exactly what that meant.

When I entered 'trisomy 18 and 13'—two of the conditions Helena had mentioned—Google returned over 700,000 hits. Far from the medical jargon I had expected, much of the data was delivered in close to layman's terms, and provided at least a cursory explanation of these disorders and their likely outcomes. Pregnancy and parenting web site BabyCenter.com explained chromosomal anomalies in the following way.

Chromosomes carry all our genetic material:
having the right number in every cell is crucial to

normal development. We should all have 23 pairs of chromosomes. At the moment of conception, 23 from the father's sperm and 23 from the mother's ovum (egg) come together to form a new life. Mistakes can happen during this process and when they do, most will miscarry ... Sometimes, though, the pregnancy continues with a baby that has either too many or too few chromosomes, or sometimes with pieces of chromosomes mixed up or missing.⁶

A 'trisomy' occurs when either the egg or sperm cell contributes an extra chromosome to the embryo, resulting in the presence of a third chromosome rather than the usual pair. A baby diagnosed with trisomy 21 (Down syndrome), for example, will have an additional copy of the number 21 chromosome in its cells. When trisomy occurs in every cell of the body, it is called a full trisomy.

In some cases, only part of the chromosome is duplicated. This is referred to as a partial trisomy. When an extra piece of one chromosome is attached to another chromosome, a translocation results, or if some of the body's cells contain an

additional chromosome while others have the usual 46, it is referred to as mosaicism.

Babies with trisomy 18 or 13 generally have a combination of congenital disorders. Many will have serious developmental disabilities as well as visible physical malformations. In some, external physical symptoms will be less obvious while internal organs such as the heart will be severely underdeveloped. Statistics on life expectancy vary, but those I accessed on that first night of searching generally suggested that 20–30% of trisomy 18 and 13 babies die within a month of being born, many within the first twenty-four hours. Ninety per cent will not see their first birthday, and only 10% will survive beyond their first year of life. While these conditions are not, as reports of long-term survivors prove, universally fatal, the medical fraternity considers statistics on survivability sufficiently grim to justify the prognosis ‘not compatible with life’.

By two the next morning I had viewed countless medical descriptions and statistics, none of which offered much hope. My eyes burned from tiredness and too much screen-time, and my head and throat throbbed from the strain of holding back tears. I bookmarked a number of items I’d skipped, and logged off.

When my nose had stopped running and I could trust myself not to snort, I crawled into bed beside Gabe and wrapped him in my arms. It was sometime after five when I finally made it to sleep.

Chapter 2

The diagnosis

Tuesday, March 6

Dr Kate Connolly greets us in the waiting room and escorts us into the same darkened cubicle I visited yesterday. As I adopt the required position on the bed and Paul takes a chair beside me, Dr Connolly explains that she will be assisting Helena to review the specific markers detected during my first visit. The scan begins and Paul and I are slowly talked through the specifics of what we are seeing, starting from the top.

Daniel's brain appears to be missing part of the vermis, which is a structure connecting the two hemispheres of the cerebellum—a part of the brain responsible for coordinating bodily movements. The prognosis based on this marker alone could be anything from

severe intellectual disability to no intellectual impairment. This problem may or may not be the result of a chromosomal disorder. All other parts of his brain, as far as anyone can tell, appear to be present and well formed.

Viewing a frontal perspective of Daniel's face, Dr Connolly suggests his eyes may be too wide-set, another possible marker. A more thorough look at his limbs and extremities reveals nothing of concern, while further examination of his kidneys confirms they are functioning, though measurements suggest they are slightly larger than average.

It takes a long time to capture the required perspectives of his heart which, Dr Connolly explains, is divided into four chambers consisting of the left and right ventricles and atria. In a healthy baby, both sides should appear roughly symmetrical. But Daniel's left heart is significantly smaller than his right—a problem that in the vast majority of cases increases as pregnancy progresses and can prove life-threatening. Additionally, we see two white spots known as echogenic intracardiac foci, another marker often linked with chromosomal abnormality.

I stare at the chalky features while Paul hangs his head and puts his face in his hands.

After more than an hour of searching, Doctors Connolly and Johnson find nothing to allay their earlier concerns. Both suspect that a chromosomal problem is most likely, but emphasise that this can only be confirmed through amniocentesis.

We have a decision to make.

Before Daniel, amniocentesis was just the title of the section I always skipped as I flicked through the stack of pregnancy guides I'd accumulated. I knew it involved the withdrawal of amniotic fluid via a needle inserted through the abdomen into the uterus, and that it carried at least a 1-in-200 chance of miscarriage. Based on these factors alone, I had always thought of it as a scary invasive manoeuvre to which I would never consent.

Dr Connolly explained that the procedure served three main purposes in a situation such as ours. First, and most obviously, it allowed parents the option to end the pregnancy should they be unwilling to give birth to a baby with serious and potentially fatal disabilities. Secondly, it enabled parents and their doctors or midwives to plan the birth most appropriate to the baby's needs, and consider how best to manage specific congenital problems. Finally, proof of a chromosomal disorder could

influence the obstetrics team's advice in terms of how the baby should be delivered. For example, should amniocentesis confirm a condition deemed to be not compatible with life, obstetricians would typically be less likely to recommend a Caesarian section during labour, regardless of whether foetal distress was evident. In this case, a mother's health and viability for future vaginal deliveries may be prioritised due to the poor expected outcome for her baby.

Knowing there were sound reasons to justify undergoing amniocentesis did not make our decision any easier. Further reading told me that potential complications include amniotic fluid leakage, vaginal bleeding, and injury to the baby, with conflicting views on just how often these problems occur. And while 1-in-200 is the most commonly quoted statistic for the risk of miscarriage as a result of the procedure, estimates range from 1-in-160 to 1-in-300. A typical genetic amniocentesis result will show whether the correct number of chromosomes is present, and whether there is an increased risk of some birth defects like open spina bifida. It will not show whether the baby has other inherited or genetic disease unless specific testing is requested.⁷ If we chose to proceed, Paul and I would essentially be risking

our baby's life in order to put a name to his condition. If Daniel's anomalies were related not to a chromosomal disorder as suspected, but to some other syndrome, we may not even achieve this much.

Despite my doubts, I did not see how we could make informed choices for Daniel without all the available information. If amniocentesis ruled out a chromosomal disorder, it may be that his problems were treatable, in which case we would need to research our treatment options and make plans to deliver him where the appropriate specialist care was available. Ultimately, compared with the idea of spending the next twenty weeks wandering blindly through the land of what-if, the scary invasive procedure seemed at least a *little* less scary.

Friday, March 9

Paul and I sit close together in the Radiology waiting room, flicking through dog-eared copies of New Idea and Women's Weekly. I was here just last night when, at my request, my obstetricians agreed to conduct a further ultrasound. I had hoped that another look might divulge something to suggest that Daniel's condition was less serious than first suspected. Instead it revealed a previously unnoticed sixth

digit on Daniel's left hand, a marker most commonly associated with trisomy 13. So here I sit just sixteen hours later preparing to undergo amniocentesis, something I thought I would never do.

Everyone is punctual, and I'm sprawled on the now familiar mattress by 8.05. Helena will conduct the amnio. Her assistants are Dan and Liz. I am surprisingly calm. A quick scan locates Daniel, the placenta, and a clear spot on the left of my uterus. The procedure takes no more than a few minutes. Liz swabs my belly with antiseptic solution and Helena delivers a local anaesthetic. My eyes shift back and forth from my belly to the ultrasound monitor as a long needle enters my abdomen. There is a feeling of slight pressure as it penetrates, then I feel nothing as I watch the clear phial slowly fill with straw-coloured liquid. Physically, it is less traumatic than a blood test. Mentally, I can't fight the feeling that this is by far the most unnatural thing my body has ever been subjected to. Some cotton wool and sticking plaster, a quick check of Daniel's heartbeat, and we're good to go. Paul and I walk the samples over to the pathology lab.

The initial results of Fluorescent In Situ Hybridisation, commonly known as the FISH test, should be in on Monday or Tuesday. This will confirm the existence of certain chromosomal abnormalities, but

will not provide a comprehensive picture of how many of Daniel's cells are affected. Full results and the complete diagnosis will follow in ten to fourteen days. Until then, it's hurry up and wait.

Tuesday, March 13

I phone Helena at eleven. She will get back to me within the hour. The phone rings twice in the space of twenty minutes. Both times it's telephone company cold-callers. Helena phones sometime after twelve. The news is not good, she tells me. The FISH test has confirmed the presence of an additional thirteenth chromosome. Full results will not be available for a further two weeks, but Daniel clearly has trisomy 13.

Termination, she says softly, is a definite option. Northern Territory law dictates this must be performed by twenty-three weeks, I am coming up to twenty-one. What exactly does that involve? I ask. The voice I hear is calm and flat. I cannot believe it is my own.

I will go to the hospital, Helena explains, where I will be admitted to the birth suite. The rostered obstetrician will insert Misoprostol suppositories into my vagina at four hourly intervals to induce labour. Because it is so early in my pregnancy, no one can predict exactly how long it will take for contractions to begin, but

hopefully no longer than a day. Should I suffer side effects from the medication, such as vomiting or diarrhea, I will need to wait longer between each application, in which case the onset of labour will be further delayed. Once contractions start I will be offered gas and Pethidine for pain relief. Eventually I will vaginally deliver my son who, even if he survives labour, will be too small and weak to do anything but gasp for the breath his underdeveloped lungs cannot receive. Then his father and I will watch him die.

I thank Helena, hang up the phone, and relate all she has told me to Paul. He sits down beside me, puts his arms around me, and cries.

Chapter 3

No matter what

Part of me had been so sure there was a chance we were dealing with something other than a chromosomal abnormality—maybe even something that could rectify itself as Daniel grew, or turn out against all odds to be significantly less serious than first believed. Once the amnio results were in, denial was no longer possible.

My first phone call after hearing the news was from one of my closest childhood friends. Expecting her second child in just five weeks, she did not yet know about my pregnancy. She listened quietly as I told her of Daniel's condition and its likely prognosis. 'I'm so sorry,' she said, and paused just a beat before

asking, 'Are you going to take care of it now?' For a moment I was stunned silent, my mind turning somersaults as it tried desperately to reject the notion. *Was* I going to 'take care of it' now? The idea of making a conscious decision to end my baby's life was inconceivable. Or was it?

Certainly before Daniel's diagnosis we felt we could love and accept a child with physical or mental disabilities no matter how severe, hence our decision not to undergo screening during the early stages of my pregnancy. But a diagnosis like trisomy 13 brought with it a whole new set of considerations, foremost among them the question of whether our baby would be born to a life of suffering.

The catalogue of congenital defects found in babies with full trisomy 13 is extensive. Just some of the notable physical differences include small head size, small eyes, cleft lip or palate, additional fingers or toes, and abnormal foot development. Heart and kidney defects are found in 80% and 30% of cases respectively. Parts of the brain may be absent or underdeveloped, causing varying levels of intellectual disability and affecting the growth and function of other structures and organs. Many babies experience breathing and feeding difficulties, and those who

do survive early infancy are often prone to visual problems and hearing loss.⁸ These examples are plucked from the much longer list of recorded symptoms on which medical professionals base their advice.

What no one can predict before birth is which, or how many, of these symptoms will be present. While ultrasound and other forms of testing may pick up some likely manifestations, no prenatal test can accurately predict length or quality of life. How then, could we justify ending our baby's? Emotionally, I knew termination would be a devastating choice, yet I felt we owed it to Daniel to at least consider whether it would be the more compassionate one.

I did not need to review the physical symptoms or morbidity statistics for Daniel's condition—they were already etched in my brain. So that night, when I typed the now familiar query into Google, I was looking for something more than the standard medical spiel. I was looking for hope. Following a link titled 'Abigail's Story', I found it. There, on sites like LivingWithTrisomy13.org and BeNotAfraid.net was clear and extensive evidence of trisomy babies surviving to term and beyond. And pages filled with words of support and encourage-

ment from parents who chose to hold and love these babies for as long as they could, cherishing their lives, however brief.

There were pregnancy diaries, labour stories, birth plans and photographs. Some of the babies had prominent physical malformations, but all I could think as I studied their faces was that each was so precious and unique. Many had lived just a few short minutes, but of all the parents who described their bittersweet journeys, not one expressed regret, only inner peace and deep gratitude.

The personal accounts of those who had decided to terminate their pregnancies presented a very different picture. I was shocked and saddened by stories of women who felt pressured by medical professionals, friends, and even family members, to end their babies' lives, all the time unaware that many trisomy babies make it to term and that some, albeit a small number, do survive in the longer term. I do not dispute the right of any woman to choose to end her pregnancy, but does the word 'choice' still apply when a decision is based on incomplete information, inaccurate medical advice and coercion?

While my own obstetricians had advised me of my option to terminate, at no time did they suggest that this would be my only,

or even the better choice. They did not deliver callous, worst-case-scenario speeches about how badly deformed my baby would be, or insinuate that keeping him would be unkind or irresponsible. Instead they told me that the decision was entirely mine, and that, should I decide to proceed with my pregnancy, they would be happy to look after me. Many mothers in my position have not been so fortunate.

Later that night as I lay awake, I tried to ignore the familiar tumblings in my belly, but was powerless to prevent my hands from performing their nightly ritual. As my fingers traced soothing rhythmic circles on my abdomen, I thought of the flaccid skin dimpled like a sunken sponge cake that would replace the tautness of my growing bump, and of the horrible emptiness that would accompany the physical loss. It was then that I thought again of Gemma and Kia and Eli and the countless other babies whose stories had so inspired me. Their parents had photographs and memories that would stay with them forever.

Should Paul and I choose to terminate, this time next week we would have only a lifetime of what-ifs. And even as the tears came, fat and silent, I felt something shift inside me as despair gave way to hope.

Our midwife, Marg, was interstate when we received Daniel's diagnosis, but she phoned on Thursday morning, just hours after stepping off a late-night flight, to see how we were. She was at my door a few hours later, tissue box in hand. When I collapsed in tears, she hugged me tight and told me it was okay to cry and not to spend all my time trying to hold it in. We sat at my kitchen table, and over cups of peppermint tea I explained what I was considering and why.

I told her how the thought of inducing labour at just twenty-two weeks sickened me, and that I could think of nothing more frightening than the idea of luring Daniel with drug-induced contractions from his safe, warm space inside me. I told her that I didn't know if I could bear to watch Paul watch me terminate our child, and that, even if I agreed to the procedure, I was sure that when the crunch came I would be unable to go through with it. I told her that while every instinct in my body screamed at me to keep my baby, I was terrified that he would suffer if I allowed him to be born. And I told her I didn't know which course I feared more.

I did not tell Marg that if I chose termination, I would want no one, not even my closest friends or family members, to know.

Marg said that everything I was feeling was perfectly natural and that she would support us whatever our decision. She asked whether I felt I had all the necessary information, and ensured I was fully aware of what termination at this stage would involve. Perhaps, she suggested, if I was so traumatised by the thought of ending my pregnancy it was a pretty good indication that it wasn't what I needed to do. Finally she explained that, depending on our intentions for Daniel's immediate postnatal treatment, it may be possible for us to deliver him at home as planned. Alternatively, if we felt the need to go to hospital, she would stay with us throughout the labour, ensuring to the best of her ability that all our wishes for Daniel were adhered to. After Marg left I realised I felt good, and found myself able to think clearly for the first time since my initial scan.

I have always considered myself pro-choice and advocate a mother's right to make decisions for herself and her unborn child. What I underestimated, before Daniel, was just how personal those decisions can be. Many parents I know have undergone all available prenatal screening, adamant that they would terminate should serious abnormalities be found. For some, the choice is purely pragmatic: they acknowledge that

many babies born with disabilities go on to lead productive and happy lives, but feel they do not have what it takes to successfully parent such a child. Others I have spoken to are concerned about the impact a child with special needs would have on the lives and futures of their existing children. Then there are those who feel that a decision to knowingly bring a disabled child into the world is irresponsible, even cruel. A life marred by physical or mental incapacity, they argue, is essentially not worth living, and something that modern medical technology should be able to detect and prevent. There was a time when I might have empathised with all of these perspectives. But that was before Daniel.

After the diagnosis I was offered a lot of advice from well-meaning friends. ‘Oh well,’ shrugged one for whom a choice to terminate was a foregone conclusion, ‘you’re still young enough to have another one.’ ‘I know it’ll be hard,’ offered another, ‘but you’ll be able to put it behind you and move on.’ They spoke as if ending my pregnancy at twenty-two weeks would be no more traumatic than having a tooth yanked. To them, termination was simply the most practical option. It was only late March, I could conceive again this year. The diagnosis was confirmed, the

outlook grave. Why put myself through another twenty weeks of pregnancy when my baby would die anyway?

Birth educator and activist Sheila Kitzinger observes that in many religions termination is not considered a sin unless ‘quickenings’—the faint foetal movements felt any time between sixteen and twenty weeks—has taken place. ‘Once a woman has “felt life”,’ she writes, ‘it is a violation of the ethical code of virtually every religion [to terminate the pregnancy].’⁹

But it is not only the disciples of religion who seem to feel there is a distinct point at which the death of an unborn baby ceases to be just a sad fact of life and becomes something more tragic. One has only to look at the commonly-held perception—refuted in literature produced by and for parents who have suffered the loss of a baby through miscarriage, stillbirth or neonatal death—that a woman who miscarries early on or delivers before her baby is sufficiently developed to survive, has suffered a less substantial loss than one whose pregnancy progresses to term.

Psychologists and grief counsellors like Margaret Nicol and the late Hannah Lothrop, who herself experienced the loss of a baby, reject this notion of a magic cut-off point, arguing that for some

women who have miscarried, the loss is intense and long-lasting¹⁰, and often more painful than is generally acknowledged.¹¹

For me, there was no set of moral or legal guidelines or regulations, no catalogue of medical statistics or expected outcomes, and certainly no socially acceptable line in the sand that could simplify my choice. In the end, I listened to my body and the primal and overriding urge to protect my child. Paul barely made it through the front door that afternoon before I told him I was sure I wanted to keep our baby. If Daniel were to die, it would be in our arms, but not at our hands. His look of relief is something I'll never forget.

'What would you do,' I asked Gabe that night as he shuffled the stack of books on the bed, 'if Daniel looked a bit different to other babies?'

'I wouldn't care,' he told me, and paused for a moment before adding, 'Maybe he'll look like Hunchy.' He was referring to the infamous hunchback of Notre Dame with whom he had become well acquainted thanks to multiple viewings of the Disney DVD.

'Maybe,' I agreed. 'Would that be okay?' Gabe nodded. 'And what if he was sick when he was born and needed a lot of extra

looking after?’ I ventured. Gabe’s brow furrowed slightly as he studied the cover of a much-loved Little Golden Book. At last he shrugged.

‘Then I’d help you look after him.’

‘What if he was too sick to stay with us and we only had him for a really little while after he was born?’

‘You mean, like if he died?’

‘Yes, if he died.’

‘I’d still want him,’ Gabe said, handing over a library copy of Lauren Child’s *Whoops! But It Wasn’t Me*— the one where Lola breaks Charlie’s extra-special rocket.¹²

‘No matter what?’ I asked, as I opened the book.

Gabe glanced up from page one. ‘No matter what,’ he said.

Those three words pretty much covered it. Not so surprising, I thought, that they should come from the mouth of a babe.

Chapter 4

A 'normal' pregnancy

If the days between detection and diagnosis were among the loneliest of my life, those that followed our decision to keep Daniel were the opposite. Family members and close friends supported our choice, and as people reached out in sometimes unexpected ways, we were truly overwhelmed by their many gestures of kindness and reassurance.

Determined to surround ourselves with positive energy, we decided that only those closest to us should know of our situation. The relentless nausea and frequent vomiting I had experienced until my twentieth week had finally stopped, and I wanted the chance to enjoy the second half of my pregnancy minus the

looks of sympathy and probing questions that would inevitably follow widespread news of Daniel's condition. I needed to be able to bask in that lovely second trimester glow and channel my newfound energy into appreciating every moment with this special baby. I wanted to spend the rest of my pregnancy like any other mum-to-be: taking prenatal exercise classes, having foot massages, decorating the baby's room and nesting.

But the reality of Daniel's condition was not something we could ignore, and with that reality came responsibilities that no expectant parent wants to bear. Discussing what to do with our baby's body if and when he died felt morbid and unnatural. Both Paul and I acknowledged it needed to be done, but could not shake the feeling that considering such decisions at this point reflected a lack of faith and a willingness to give up too soon.

The support of those around us was a godsend. A good friend who had lost her own baby daughter two years earlier openly shared her experiences, and convinced me that preparing for what *may* happen in no way betrayed Daniel or undermined our belief that he could survive. Gabe's school pastor gave us welcome advice on cremation and burial and offered to lead a service for Daniel in our chosen place and format should the

need arise. And my mum made inquiries into having Daniel's body transported from Darwin to Queensland should we decide to bury him alongside his great grandparents in my hometown cemetery. Ultimately it was the fear of having to make these decisions later, in the midst of our grief, which prompted us to think seriously about how and where we would like to lay Daniel to rest. It was, we assured ourselves, a just-in-case measure.

In early April we flew to Queensland to spend Easter with my family, and were met at Brisbane airport by my sister Cyndie, radiantly pregnant with twin girls who would make their appearance sometime in June, just a month before Daniel was due. The following day we drove three hours south to our hometown of Wallangarra, and on Easter Sunday accompanied Mum to visit our grandparents' graves.

Accessed via an old dirt road, the Wallangarra Cemetery sits on a sloping stretch of ground, encircled by tall gums and old pines, just off the New England Highway on its last southbound stretch into town. The hill and the trees lend the illusion of solitude, with only the low rumble of traffic and the familiar warble of magpies breaking the silence. In all the times I've visited, I've never bumped into another living soul.

On the day of my grandfather's funeral it was late summer, and the air was thick with humidity but no real promise of rain. I remember the dead grass crackling under my feet and how everything seemed so grey. Two years on, the huge trees that once lined the back fence are gone, the drought has worsened and the place looks starker still. But here, in the row closest to the road, lie my Nana and Pop, two of the people in my life I have most adored.

Nana was, to me, the epitome of kindness. When I was small she would sit on the stairs and balance me in the folds of her old pink nightdress, swinging me back and forth as she sang in her high sweet voice. Long ago lullabies, classic hymns and children's prayers were handed down from Nana to her grandchildren as she rocked each one of us in turn. Long, twisted barley sugars, grilled cheese on toast, and the smell of Pears baby soap all remind me of Nana. She would cut us fresh oranges, leaving only the seeded centre standing while the remaining pieces of juicy flesh fanned out in eight neat segments around it. Nana gave me my first bible, taught me *The 23rd Psalm*, and long after I'd entered adulthood still sang 'Let the sun shine in' whenever she saw me cry.

And Pop, standing over his old gas stove, stirring a pot, his big square-rimmed glasses fogging up as he filled the kitchen with

the aroma of authentic Ceylon curry. ‘Oh come all ye faithful, come and eat a plate full!’ My memory favours him in his faded blue overalls—the ones he donned to crawl beneath his car and tinker, or tend to his tomato plants, or fix Mum’s washing machine. Beneath them he smelled of Imperial Leather and Old Spice. His hair was thick and wavy, slicked back, always immaculate. He would dip a serving spoon into the pot and blow it for a moment before lowering it to my lips and arching his dark silver eyebrows in anticipation.

For so many reasons there are no two people to whom I would more willingly deliver my babe.

Paul and I stood close together, arms entwined, and watched our two-year-old niece, Mia, dance around their graves while Mum plucked dead weeds and rearranged the flowers. It didn’t seem such a stretch that we could find peace with the idea of Daniel lying here, if only it didn’t mean he would be so far from us.

I knew then it was too soon to decide. And in that instant I was sure there was time enough not to.

When Marg arrived for her April visit, she brought my notes from the hospital. Among them were the results of my ultrasound

scans, including a list of foetal measurements and a one-paragraph description of what was detected. The report was signed by two doctors I'd never met, and it seemed wrong that they should know so much about my unborn son.

After Marg had done her usual bit—had a cuppa and a long chat, felt my belly and listened to Daniel's heartbeat—and Paul had left for work, I reread the ultrasound report, and logged-on to the net to query each of Daniel's noted anomalies. Some of them I didn't even recall, discovered perhaps during a comparison of all three scans, or mentioned but lost on me in my initial state of shock. In any case, based on this report Daniel had a posterior fossa cyst, mild ventriculomegaly, hypertelorism and micrognathia. Translation: there was a cyst in the back of Daniel's brain and his ventricles were slightly enlarged. As noted previously by Doctors Connolly and Johnson, his eyes were wide set, his jaw receding, and he had an extra digit on one of his hands. His kidneys, the report noted, were echogenic and his heart was 'possibly' hypoplastic, meaning underdeveloped. There was no mention of a missing or undersized vermis.

I sat before my computer, belly jumping periodically as Daniel hiccupped and, for the first time in weeks, I cried and cried.

Seeing my baby reduced to a list of morphological abnormalities compiled by strangers who would never know his name was devastating. It seemed such a terrible invasion of his privacy, a betrayal of his most intimate secrets, and suddenly I was angry with myself for exposing him to the scrutiny of outsiders.

I thought then of some photos I had recently discovered on the net. Not those shared by grieving parents, proud of their babies and hoping to offer comfort and inspiration to others, but those found on medical sites illustrating the clinical manifestations of various anomalies. Nameless babes are identified only by captions like ‘Newborn male with full trisomy 13’, or by the list of symptoms they display—‘cleft palate, atrial septal defect, inguinal hernia, postaxial polydactyly’. Did their parents consent to this? Did they say, ‘Yes, you can photograph my child and place his image where all the world can see, highlighting his flaws but completely failing to acknowledge that he was someone’s baby, a little person, so much more than a set of congenital defects’? *Daniel’s our baby, I had a sudden urge to scream to the world. He’s Gabe’s little brother, and a grandson and a nephew and a cousin.*

But my anger was fleeting, and a minute later I could see the black and white typed report for what it was—the medical

assessment of a nineteen-week-old foetus who also happened to be my son. I sat a while longer, my hand on my belly, then neatly folded my hospital notes and placed them in the back of the little orange plastic sleeve containing my pregnancy record. It would be a long time before I could bring myself to look at them again.

As the wet season left us and fireflies signalled the coming of the dry, I revelled in my second-trimester stamina, lapping up the frequent compliments about my glowing skin and shiny hair and cute little bump. Sometimes I almost forgot about Daniel's condition and felt just like any other expectant mum. I swam, walked the dog, cycled to and from school with Gabe, rubbed cream into my belly at night, and gave myself weekly facials and foot soaks.

Each bedtime Gabe would choose two songs—one for his brother and one for him. Most often it was 'Danny Boy' or Elton John's 'Daniel' followed by family favourite 'Two Little Boys', but sometimes he'd request a lullaby remembered from infancy or one of the rock classics with which Paul and I had successfully indoctrinated him. Lying with one hand on my belly, Gabe would giggle occasionally at the frequent ripples or sudden jolts, and sing along between yawns. We never missed a night.

As we existed in this surreal cocoon of hope, the nagging sense that I should be doing more was ever-present. I had read of parents in similar situations choosing not to buy baby clothes or decorate a nursery, but for us it was important to prepare for our new baby, regardless of how long we would keep him. So one weekend I tore the many bags and boxes of Gabe's old clothes from their hiding places in the tops of wardrobes and under beds. I stood for hours in the heavy humidity, ceiling fan whirring full-bore above my head, and sorted and packed by size and age, then stored the neatly labelled parcels and boxes within easy reach. As I sifted through the piles of infant jumpsuits, singlets and leggings, examining each item for holes and stains, I felt an intense longing and the same giddy anticipation that had filled me while I waited for Gabe.

I nagged Paul incessantly to finish the downstairs storeroom, which we were converting to an office to free up our spare room for Daniel. Though I knew he would be sleeping with us, I wanted a baby's room no less beautiful than the one we had prepared for Gabe six years earlier. It was strange comparing my feelings when Gabe was due to what I was experiencing as I carried Daniel. With Gabe there had been nothing to detract from the expectation or

the joy. As he rumbled around in my belly I could safely envisage him crawling, walking, saying his first words—there was no reason to believe he would not achieve all those milestones. It hurt to imagine Daniel at three weeks, or eight weeks, or six months, but it hurt much more not to. So I would allow myself, I decided, to dream of what *might* be.

Until hope and reality collided, until he was taken from me, I would allow myself.

Chapter 5

Impossible choices

Tuesday, May 1

I sit alone in Radiology waiting for Helena. There are no new trashy mags so I settle for the recipe section of Better Homes and Gardens. Staff members file past me on their way out the door, some nodding and smiling, others ignoring me completely. I recognise Dan and Tim from previous visits. Both say g'day but neither gives any sign he remembers me. I've almost memorised the ingredients for salmon fettuccine when Helena arrives.

Head down, shirt up, gel on. Helena asks me how I am, then takes a moment to locate Daniel's head, body and limbs. Currently he's breech. Even if he stays that way, she'll be recommending a

vaginal delivery—am I okay with that? Yes, I tell her, it's already been explained to me that the health of my uterus and my capacity for future normal deliveries will be a higher priority than preserving Daniel's life.

The scanner slides left then right, pausing here and there to capture and measure. Helena is gentle but Daniel, I can tell, is not happy. He kicks furiously at my bladder, head butts my belly button and, just as we're getting a clear view of his heart, develops the hiccups. Poor little bloke, I think. Can't we just leave him alone?

Again the heart takes ages. Helena is quiet, staring at each image for the longest time. At last she explains that the left side is not nearly as underdeveloped as earlier scans suggested. There is still some disproportion but it is less significant than expected. My own heart does a little leap before my brain can yank it back down to earth. Does this improve his chances of surviving short-term? No, Helena tells me, it's still very variable.

After almost an hour there is an almighty kick to my lower abdomen and Helena says enough. I readjust my clothes and sit cross-legged on the bed while she calculates Daniel's weight. At just over 700 grams he's a little below average. She'd like to do another scan at around thirty-two weeks. Will anything we find help to

better predict life expectancy or influence her recommendations for Daniel's birth? Most likely not, Helena tells me. Why then, would I put myself and my baby through this again? The question hangs between us, unspoken, and we sit in silence for just a second before Helena turns back to the screen and I swing my legs to the floor. You know you can call me any time, she reminds me, as I turn to go. Thanks, I tell her, I know.

Choosing the way in which your child will enter the world and how you will subsequently care for him is confusing enough when a healthy baby is expected. For the parents of a baby with a potentially fatal condition the choices can seem impossible. Paul and I had carefully considered our options for Daniel's birth long before his diagnosis. When Gabe made his entrance it was via a series of painful interventions that resulted in a long, traumatic labour and ended in a forceps delivery. While both of us escaped relatively unscathed, I had no desire to repeat the experience. Home birth remained an option in the Northern Territory, and after a great deal of research, we had decided that this was the right choice for us. Of course Daniel's diagnosis was cause for re-examination.

From the outset, my obstetricians recommended that I deliver Daniel vaginally, regardless of any indications of foetal distress during labour. In their view, the only justification for a Caesarian section would be if *my* health were at risk. Their advice, I realised, was based on sound medical reasoning. Daniel, in their professional opinions, was going to die. Perhaps not immediately after birth, though this was most likely, but almost certainly before he reached twelve months of age. I, on the other hand, was healthy and most likely capable of conceiving and delivering ‘normal’ babies in the future. The risks associated with a Caesarian delivery were too great when compared with the likely outcome. But there was no place in their logic for a mother’s instinctual desire to protect her child, and I struggled desperately with the idea of placing my own wellbeing before my son’s. I was not concerned about preserving my uterus for babies I might never conceive; my responsibility was to do the very best I could for the child I was carrying. What I needed to know was whether delivery by C-section would, in fact, improve Daniel’s chances of survival.

Medical information comparing the outcomes for trisomy 13 babies, based on their methods of delivery, is virtually non-

existent. The most current accessible data was gathered by ThereseAnn Siegle, founder of the web site LivingWithTrisomy13.org, through a survey¹³ conducted to investigate the common trisomy 13 experience. ThereseAnn compared the outcomes for babies born by spontaneous vaginal delivery, induced vaginal delivery, vaginal birth after Caesarian, and planned and emergency Caesarian sections, with results suggesting a low correlation between methods of delivery and survival times.

I had read of doctors recommending C-sections due to specific anomalies such as omphalocele—where intestines or other abdominal organs are pushed out into the base of the umbilical cord and form outside the body—which make vaginal delivery dangerous or sometimes impossible, and also of trisomy 13 mums insisting on this method in the belief that a quicker birth would be safer for their baby. But my ultrasounds had revealed nothing to suggest that Daniel would be at greater risk if he were delivered vaginally.

Given the medical advice we had received and the results of my own research, both Paul and I felt that homebirth remained a realistic alternative, but first we needed to better understand our choices for Daniel's postnatal care. It had already been explained

to us that few Australian doctors would recommend any form of aggressive medical treatment, or what some refer to as ‘heroic measures’, for a baby with a life-threatening chromosomal disorder. Should Daniel suffer from a severe heart complaint such as hypoplastic left heart syndrome, for example, cardiac specialists would be highly unlikely to attempt the series of operations usually offered to other heart babies. Performing surgery to correct damage to one particular organ is viewed as futile when it is unlikely to result in an improved overall outcome. Even the most basic of intensive care procedures would not be offered to Daniel barring an explicit request from us. The alternative, we were told, was comfort care, which essentially involves caring for your baby without medical intervention or, as many see it, ‘letting nature take its course.’

But comfort care is not the only available option for babies like Daniel. Many parents, particularly those in some parts of the United States, have found specialists willing to perform a range of medical procedures to prolong life, even if only for the short term. And as Paul and I wrestled with our consciences, trying desperately to make the most compassionate choices for our child, I was sure of only one thing—in situations like ours there is no right or wrong.

Of the trisomy 13 children and adults alive today, many have survived only because their parents rejected the option of comfort care and pursued every available medical alternative. All are living happy lives surrounded by those who adore them, and no one seeing their photos or reading their stories could fail to be inspired by their achievements, or doubt their parents' courage and devotion. Then there are the babies who have lived just a few short minutes or hours. Never having passed through the hands of strangers or beneath the surgeon's scalpel, they have quietly slipped away, knowing only their mother's touch and the love of their family. Asked to make an impossible choice, all these parents have acted in the belief that they are doing the very best for their babies and, regardless of their chosen course, the depth of their love is without question.

So what of our choice for *our* child? With no possible way of knowing how severe Daniel's symptoms would be, or how long he would be able to survive outside my womb, Paul and I felt that the most important thing we could offer him was love. Of course we wanted to keep him for as long as we could, would have given almost anything to be guaranteed just one day. What we wanted more, though, was to ensure that whatever time we did have

was spent together, that Daniel not be separated from us for any reason, that he be able to lay skin on skin with his mother, feel his father's touch, and hear his brother's voice. Most of all, we wanted to ensure that he did not suffer.

Had I believed for a moment that a C-section and an extended hospital stay would improve Daniel's chances of long-term survival, or ensure him a better quality of life, it would have been a no-brainer. But nothing I had read or been told led me to believe this was true in Daniel's situation.

One week after my ultrasound, Paul and I visited a local pediatrician to seek his opinion on our decision. A friendly bloke who listened intently and treated us with honesty and compassion, he suggested that delivering at home was unlikely to alter Daniel's chances of survival. He assured us also that should I be transferred to hospital during labour, our birth plan and wishes for Daniel would be strictly adhered to, and that under no circumstances would he be taken from us or any aggressive treatment administered without our consent.

Paul clung tightly to my hand as we left the pediatrician's office and followed the eighth floor corridor to the lift. As we stared out the window over a sea of palm trees and rooftops, I squeezed his

hand tighter and muttered something about feeling reassured, when what I really felt was numb. Everyone we had spoken to so far had insisted that Daniel's fate was out of our hands. We were being let off the hook in a sense, assured and reassured that nothing we did could alter the outcome for our son. But since my twenty-eight-week scan had revealed changes in Daniel's specific anomalies, I had been haunted by the feeling that we hadn't learned nearly enough, that there was so much more we needed to know. And as we left the hospital and headed for home, I was still no closer to shaking it.

Tuesday, May 29

Gabe's first tears for Daniel are shed at the start of my thirty-second week, and though not unexpected, still catch me off guard. Laid up with a virus, he is confined to bed for the first time in his life. We have just read his bedtime story and are about to sing to Daniel when he suddenly turns from me, refusing to put his hand on my belly or even choose a song. When finally he will let me see his face, his lip is trembling and his cheeks are wet. He looks at me through round black eyes shadowy with fever and exhaustion, and tells me in a barely-there voice that he doesn't want to watch his brother die.

How easy, I think, it would be at this moment to chase away his tears with a grown-up's lie. How easy and how cruel. I wipe his face and tell him to blow, then pull him close and lay his head next to mine. It's true, I tell him, Daniel might die. No matter how much we hope or pray or wish. But he's not dead now, so we have to make every second with him count. We have to sing to him and talk to him and touch him through my belly so he will never feel alone and always know how much we love him.

After a while Gabe reaches across and places his hand just below my belly button. How will we recognise Daniel, he wants to know, when we meet him in heaven? We'll be so old, he says, and he'll still be just a little baby. We just will, I tell him as I pull him closer still, and maybe this too is a grown-up's lie. But it's the only type of heaven I can believe in for my child.

Chapter 6

Beer and Skittles

To family and friends it must have appeared as though the latter part of my pregnancy was all beer and skittles, that I bounced through each day with my head in the clouds and no thought for the reality of what was to come. It's true, most of the time I *was* elated, each kick, hiccup or head butt from Daniel launching me into a state of utter euphoria. But there were dark times, too—moments of deep depression and loneliness that arrived without warning and hit me like a wrecking ball.

On those days I was a complete bitch. I would stomp through the house sulking, snapping and grunting monosyllabic utterances, while Paul tiptoed around me, taking the hits without

complaint, and Gabe ducked for cover. They were, of course, the last two people in the world I was mad at. They just happened to be in my direct line of fire. Hormones, I knew, were partly to blame, as was the absence of a more legitimate target for my anger. Thankfully though, these wife-and-mother-from-hell days were few and far between. To let myself wallow for too long was to take something away from Daniel, to see him as less than he was entitled to be, and that I couldn't allow.

It was after a particularly dark period in mid-May that I decided to revisit some of the web sites that had so inspired me in those first days following Daniel's diagnosis. It seemed suddenly very important that I reach out to people in similar situations and seek the advice of other mums who had carried and delivered babies like Daniel. So I sent a family photo and Daniel's story-so-far into the US-based LivingWithTrisomy13.org and registered to participate in a number of online discussion groups. It was the singularly most positive step I took in my search for understanding and acceptance. Within two days my inbox was flooded with messages of empathy and encouragement from all around the world, and the thought of Daniel touching the lives of others so far away was pretty awesome.

Among the parents who contacted me, the range of experiences was broad. Some, like us, had received a prenatal diagnosis, while others did not know of their child's condition until immediately after birth, or even later. They shared stories of babies who had never taken a breath, babies who had lived for just a few short hours, and babies who had grown to become toddlers, young children and even adults. The glaring similarity in all their messages was the complete absence of self-pity. These people, some of them still in the very early stages of grieving, had found time to reach across the globe and offer words of hope and comfort to someone on the other side. I reminded myself of this each and every time I was tempted to follow the slippery downward spiral into despondency.

The other commonality that struck me as I read my many emails and browsed discussion threads, was the importance placed on spirituality. A vast majority of these parents found great comfort in the conviction that their babies were now in heaven, and despite their grief were adamant they had never felt betrayed or forsaken by God. Clearly it was from their belief in Him that they derived much of their strength, and I envied them their unwavering faith.

Though baptised a Catholic, I was raised to believe that showing compassion and tolerance was far more important than devout adherence to the doctrine of any one church. As a child I attended Sunday school, learned *The Apostle's Creed* by heart and, at the age of eleven, marched down the aisle in a pretty white dress and veil to receive my first taste of the body and blood of Christ. We were not never-miss-a-Sunday Christians, but God was a constant presence in our home, and each night before bed I knelt to recite *Gentle Jesus Meek and Mild*, *The Lord's Prayer* and *The 23rd Psalm*.

I prayed for Nana and Pop, my parents, my uncles, aunties and cousins, sick pets, a ticket to the Bruce Springsteen concert. At fifteen I tried to cut my first deal with God when I swore I'd never ask for anything again if He'd just make Stuart Arthur fall in love with me forever. God, I discovered, doesn't do deals, and Stuart's undying love was not the last thing I would pray for. But a lot of my prayers *were* answered and I never doubted the presence of a higher love.

I can't pinpoint a time when my faith officially lapsed. I don't know that it ever suffered a crisis as such, or that any one incident caused me to question my beliefs. Somewhere in the rush of

growing and living I just lost touch with this thing I had been brought up to believe in.

These days my relationship with God is what some practising Christians might see as one of convenience. It doesn't always involve church or confessionals or communion, three days out of five I forget to say my prayers, and I don't count my blessings nearly as often as I should. But I'm big on the 'do unto others' rule and I try not to be a bystander when I see someone in need of a hand. And now and then I take Nana's bible from my top bedside drawer, turn to the passages she marked with pieces of scrap paper, and read the underlined verses and the notes she scribbled in the margins. It's difficult to explain why Nana's words bring me so much comfort, but I know they're the reason that not once since Daniel's diagnosis have I asked why this is happening to me, or felt abandoned by God or nature or the universe.

I do not see God as an interventionist being who discriminately chooses to inflict illness or disability upon unborn children, or reaches down and heals them with one touch of His hand. While I do believe there is a reason Daniel has been given to us, I have no compulsion to search for what that might be—that knowledge, I believe, will come to me in time. The child in me

prays for a miracle, while the adult asks only that we be able to meet our baby, and that while he is with us—whether it be for an hour, a day, or a year—he knows no suffering and is surrounded only by love.

My faith is not so blind it will allow me to believe that Daniel will be born perfectly healthy, cured of the abnormalities detected on ultrasound, and minus the additional thirteenth chromosome revealed via amniocentesis. It is strong enough for me to know, with one hundred percent certainty, that whatever happens, we will be alright. And that knowledge, I reckon, is reason enough to be thankful.

Thursday, May 31

In my dream, Gabe and I are visiting a giant who resembles Robbie Coltrane's Hagrid from the Harry Potter films. He lives on a remote tropical island, the waters of which are patrolled by giant sharks and all manner of sea beasts. As it happens, the giant has just finished building his new restaurant—an elevated, windowless establishment with wooden tables and benches, and a high, thatched roof. The dining area juts out over the water and is accessed via a steep, narrow staircase that becomes almost completely inundated with

each high tide. Standing on the top step, stein in hand, the giant explains that one must arrive at low tide and stay on until the tide goes out else risk being ravaged by ravenous sea monsters of the most savage kind.

Perhaps it is this news that triggers my labour. Fortunately the giant's island is equipped with a first-class modern hospital that quite resembles the inside of Dubai's international airport. Marg is already waiting when I enter the delivery suite.

The labour itself is painless. Marg simply lifts my dress, says, 'He's a month early, but what the hell,' and asks me to give one good push. Out pops Daniel, already swaddled, into her waiting hands. She lays him on my chest and I study his face. His forehead protrudes just slightly above his brow, his eyes are a tiny bit wide-set and his chin is noticeably small. When he yawns I see he has what Marg calls a cleft tongue, but when I put him to my breast he drinks thirstily, his mouth clamped tightly to my nipple, his eyes never leaving mine. He is the most beautiful thing I've ever seen.

When I wake, my hand is on my belly, and I am filled with an overwhelming sense of peace. I carry the memory of his face with me long into the day.

Chapter 7

As long as it's healthy

The decision to keep Daniel's condition largely to ourselves was entirely our own, and made with the full knowledge that it would not always be easy. At no time in a woman's life is she more exposed to scrutiny than when she is pregnant, and no other human condition invites the same relentless onslaught of open inquisition and frank observation. From breast size and weight gain to birthing venues and baby names, suddenly no detail is too intimate to be discussed and dissected in the public domain.

It never occurred to me during my first pregnancy to be put out by the endless comments on my changing shape and frequent questions about everything from my baby's sex to my

birth plan. For me, such interest, albeit a little over zealous at times, was generally well intentioned and a constant reminder of new life's ability to touch all those who encounter it. Carrying Daniel has not made me change that view. It has, however, given me a somewhat unique insider's perspective from which even the most harmless of questions and statements can sometimes appear to be otherwise.

As long as it's healthy. Possibly the most frequently used of all the trite utterances fired on a daily basis at the glowing mum to be, generally a follow-up to that other all-time favourite, *do you know what you're having?* Popular variations include *as long as it has ten fingers and ten toes*, and *as long as it's got all its bits*. *As long as it's healthy*—I must have said the same thing a hundred times whilst gushing over friends' pregnant bellies. Only since carrying a baby who isn't has the gravity of those five words—innocent enough and always delivered with the best of intentions—truly hit home.

What, after all, is *healthy*? For a newborn babe to earn this all-important stamp of approval, which boxes must be ticked and by whom? Shortly after Daniel was diagnosed, I remember hearing of a baby who, during a routine ultrasound scan, was found to

be missing a finger. Despite the fact that no other abnormalities were detected and his organs, as far as anyone could tell, were all present and functioning, the parents were allegedly devastated. As the expectant mum of a baby whose condition is deemed to be lethal, I can't help but feel that the absence of a digit, unexpected though it may be, is nothing to get all worked up about. Is this small anomaly sufficient reason to see a baby as less than perfectly healthy? If so, then where do we draw the line? What of birthmarks, harelips, clubfeet, receding chins and the million other minor anomalies that may be present at birth? If these are justifiable cause for tears and tantrums in the delivery room, then perhaps *healthy* is just another over-used euphemism, and what we really mean when we smile reassuringly and deliver the standard platitude is, in fact, *as long as it's perfect*.

When I was twenty-eight-weeks pregnant I met a mum whose baby had been diagnosed with Down syndrome shortly after birth. She had undergone no specific prenatal screening so did not have prior warning of a congenital abnormality. On the day we met, her son was three-weeks-old and fast asleep against her breast. She beamed with pride and adoration as she peeled back the front of his carrier to reveal easily one of the most beautiful

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babies I have ever seen. His face was completely round, his cheeks pink and chubby, his nose a tiny button. The only outward sign of his condition was an unusually large gap between the first and second toe on each of his feet. Despite a few rough days in hospital following a Caesarian delivery, his mother had persevered with breastfeeding and he continued to gain weight and thrive. Each time I saw them he was fatter and more content, and I wondered how anyone could look at this baby and see him as anything less than perfect. Yet, by medical definition and societal expectation, he was not.

As long as it's healthy. As my pregnancy with Daniel approached its final stages, I heard those words over and over again, and each time they sounded a little more absurd. My newborn baby would not be healthy. Despite my every instinct suggesting otherwise, science and technology had assured me that once he left the safety of my womb he would be plagued with multiple anomalies that would most likely kill him. Of course no one outside my immediate circle was to know that, and each time someone patted my bump, blew kisses through my belly, even called me 'fatty', it confirmed that I was carrying a new life no less precious or longed for than any other. And whenever the usual string of

platitudes rolled off a well-wisher's tongue, it was easy enough to smile and nod even as I placed a protective hand on my belly.

'Do you know what you're having?'

'A boy,' I would tell them.

'Are you happy with that?'

'Of course,' I would say.

'Oh well, as long as it's healthy.'

'He probably won't be,' I would answer in my mind. 'But he will be loved.'

As long as it's healthy

Chapter 8

A healed heart and chubby cheeks

Wednesday, June 13

It feels like just days since I last sat on the padded bench seat outside Radiology, when in fact it's been more than a month. The reading stack has dwindled to comprise a couple of year-old fashion mags and a tatty National Geographic, so it's a good job we don't have to wait long. As Paul and I enter the cubicle, Dr Connolly pulls the curtains closed behind us, denying the outside world. Ringing phones, crying kids, frazzled parents—the sights and sounds of the waiting room fade into non-existence as I roll gracelessly onto the bed, lift my blouse and push down the elastic waistband of my preggy pants. Helena is ready with the towel and gel—we have this routine down pat.

Daniel today is very quiet, lolling around lazily, apparently oblivious to the probing device that passes over every inch of his being. Helena quickly orients herself with his position and I feel my skin prickle as my eyes follow the curve of his spine to where it ends in his rounded bottom. Ultrasound for me has never held any great fascination. I do not crave the sight of anatomical bits bobbing on a screen before me as proof of life, or view the experience as key to improved bonding with my unborn babe. But seeing Daniel at thirty-three weeks is special. Cocooned in the warmth of my amniotic fluid, he is free of pain and from the limitations his diagnosis imposes. ‘Not compatible with life’—‘inappropriate to treat’—‘genetically programmed not to live’. The baby I see is none of these things. He is just our son. And he is perfect.

Paul and I stare at the monitor as Helena and Dr Connolly systematically review each of Daniel’s known anomalies, explaining new developments as they go. His heart, they tell us, is definitely looking much better. The disproportion is now far less pronounced and, they assess, not life-threatening. This is a significant finding given earlier predictions relating to the possible development of hypoplastic left heart or a similarly lethal syndrome. Daniel’s kidneys remain slightly echogenic in appearance but there is no

evidence of any obvious abnormality. Moving to his brain, the mild ventriculomegaly noted in my initial ultrasound report is no longer evident—both ventricles now seem normal. The only remaining brain irregularity appears to be the absence of part of the vermis. Finally we look at his tiny hands where today the additional digit is clearly visible. To me it does not look at all out of place.

What we have, Dr Connolly tells us, is a definite diagnosis. While Daniel's specific anomalies are clearly not as severe as first suspected, he is genetically programmed not to live. We may have him for hours, days, weeks or months, but not years. I feel myself nodding, but in my mind I recite the names and ages of the children I've committed to memory: Kristopher 2, Kaitlyn 3, Nicholas 4, Hicham 5, Natalia 7, Karla 10, Taylor 13. Later I will be angry with myself for not speaking their names aloud. For now, though, I am content to exchange a knowing look with Paul and see my own hope reflected in his eyes.

What about his face? I ask, when Dr Connolly is finished. Can we have another look and try to get a photo? I have never doubted that Daniel will be beautiful, regardless of any physical differences his condition might produce, but I am not prepared for the cherubic form the shadowy printouts reveal. Despite earlier predictions of

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hypertelorism and micrognathia, Daniel's face seems perfectly proportioned, his beautifully chubby cheeks its most prominent feature. Paul clings to the photos, smiling broadly as he examines each one. Who does he look like? I ask him. He squeezes my hand. You, he answers seriously.

As I slide from the bed and readjust my clothing, I realise this may be the last time I meet with Helena and Dr Connolly. Marg will keep them informed of my progress, but there will be no need for a further consultation unless it is at my request. They smile and wish us all the best as we gather our things to go. We're here if you need us, says Dr Connolly softly. I have no doubt she means it.

For a time I had balked at the idea of undergoing a further ultrasound scan. With a conclusive diagnosis already in hand, and my obstetrician's advice that nothing they found now would alter Daniel's prognosis, I didn't really see the point. But as my thirty-second week came and went, I found myself needing to know more. Perhaps because Daniel's problems seemed so minor when compared with those noted in many trisomy babies, I found it harder to accept that they could actually threaten his life. I did not doubt the accuracy of the amniocentesis results, but having

further researched trisomy 13 and spoken with the parents of many survivors, I was no longer convinced that the condition was the definitive death sentence most medical professionals believed it to be. It therefore seemed very important to understand everything we could about Daniel's specific anomalies rather than basing our decisions for his care on the trisomy tag alone.

With these thoughts in mind I visited Dr Jo Wise, a local pediatrician who had treated Gabe three or four years earlier. I recalled her as friendly, thorough and down-to-earth, and knew I would feel comfortable discussing our plans for Daniel's birth and postnatal care with her. Before the visit I prepared a hard copy file of all the information I had collected on Daniel's condition, including photos and life stories of some of the children and adults from the LivingWithTrisomy13 web site.

After listening to my concerns, reviewing Daniel's anomalies, and reading the material I had compiled, Dr Wise agreed that it would be wrong to automatically assume that Daniel would not make it to term or die immediately after birth based solely on his trisomy 13 diagnosis.

While in her experience trisomy 13 did generally mean multiple life-threatening anomalies, she could see from the

information I had collected that some trisomy babies had survived for months and even years. Dr Wise believed that Daniel should be cared for according to his individual needs, and offered to review my ultrasound results and refer me to a cardiologist. If Daniel's heart had improved as much as my most recent scan suggested, we could at least rule that out as a likely cause of death in the immediate neonatal period.

I left Dr Wise's office with mixed emotions. I felt a great gush of gratitude that she had been able to see Daniel as an individual and was willing to treat him and care for him as she would any other baby, that she hadn't based her advice on the trisomy label alone. But I was also confused. Dr Wise had made me feel like it was all right to hope and to plan for a birth and a life instead of a death. But her advice also caused me to question our decision to deliver Daniel at home. I had researched home birth extensively and believed that in the case of a low-risk pregnancy where a healthy baby is expected, home birth was no more dangerous for either mother or baby than a hospital delivery.¹⁴ But Daniel was not a completely healthy baby. Were we taking unnecessary risks by choosing not to have him in hospital with medical staff and technology on hand?

I discussed this with anyone who would listen—my parents, sisters, midwife, close friends. But the discussion was always circular, beginning and ending with the question of what we wanted for Daniel. We wanted him to live, but we did not want him to suffer. Could we have it both ways?

I spent many hours trawling the *LivingWithTrisomy13* pages, reading about the kinds of immediate assistance each baby had needed, and trying to understand why some survived and others did not. But all I really learned was that each trisomy 13 case is unique and that before birth *no one* can accurately predict what these babies will be able to do or how long they will stay.

It would seem obvious that those with fewer detectable anomalies fare better, but this isn't always the case. As parents from the *Living* site explained—echoing the advice I had received from Dr Wise—some of the problems present in trisomy babies are not detectable before or even after birth.

A baby who displays no physical manifestations of the condition and appears to be completely healthy may die because of anomalies relating to brain function, anomalies no one can see or predict. Laurie-Beth Brennan RN, Certified Grief Counsellor, Neonatal Intensive Care Nurse and Perinatal

Hospice Coordinator, offers this explanation, based on her broad experience with trisomy 13 cases.

You can have a baby with several major anomalies who will survive long term, and then you will see babies with very few visible anomalies detected by diagnostic means, who do not survive long after birth. It is not just the presence of the anomalies themselves ... it is the presence of the extra chromosome in every cell. That chromosome can express itself in ways that may not be seen or detected by normal diagnostic means, and often affects basic bodily functions, like breathing and temperature control. It is not necessarily the anomalies themselves that are fatal, it can be a combination of the anomalies and how the trisomy 13 adds to them—or it can just be how the trisomy 13 expresses itself on a cellular level.¹⁵

The results of my most recent ultrasound suggested that none of Daniel's anomalies would be life-threatening in the short term. His heart problems were minor and all other essential organs appeared to be present and functioning. Yet this was no guarantee

that undetected problems with his brain would not produce other symptoms that could threaten his life after birth. Many trisomy babies have identifiable anomalies that can be treated to increase their chances of survival and improve their quality of life. But Daniel's case was different. How could doctors treat what they could not see?

My mind a muddle of pros and cons, I decided to take some time out and await the cardiologist's assessment. Later that week I received an email from Dr Wise. Barring any obvious problems with Daniel's heart, and given our wishes for his immediate postnatal care, she did not feel that homebirth would pose a greater risk to Daniel than it would to any other baby.

For the time being at least, I was comfortable with our decision to bring our baby into the world as gently as possible and love him as much and for as long as we could. It was never our intention to 'just do nothing'. If Daniel was born with previously undetected anomalies that caused him pain or discomfort we would, of course, seek specialised help immediately. Barring this, Marg was equipped and trained to provide basic resuscitation in the form of blow-by oxygen, and assisted ventilation via a bag and mask. We would not sit by and watch our baby struggle for breath, but

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we would not allow a machine to breathe for him. There would be no tube inserted into Daniel's windpipe. He would not be placed on advanced life support of any type.

Marg was aware of our unique needs, and had assured us that we would have her full support should we change our minds and decide to transfer to hospital at any stage. Somehow though, I suspected that this was a decision Daniel might make for himself.

Chapter 9

Perfect

Saturday, July 7

The first contraction is strong enough to wake me. Eyes still shut, I roll onto my side—maybe I dreamed it. But when I feel the second one, a wave of recognition sweeps over me. Not yet, little man, I whisper, it's not quite time. I flick on the bedside light, reach for my borrowed copy of What to Expect When You're Expecting, and turn to the section on false labour. Satisfied that's what I'm experiencing, I turn off the light and again close my eyes. I ignore the cramps for what seems like a long time—they're mild and irregular, nothing to worry about. But I fumble for my watch just in case then suddenly remember the loads of dirty washing in the laundry and the gritty floorboards in my lounge room. It is 4.15 when I start cleaning.

Only after I've swept and mopped the floor and put on a load of washing do I return to bed. When I wake at six the contractions are still mild and fifteen minutes apart. I'm up by seven, and by eight Paul is shifting furniture and cleaning walls. We haven't finished Daniel's room yet, we thought we'd have more time. I phone Mum, Marg and my sister Cyndie. Mum will try and change her flight. Marg will bring the birthing pool over sometime after 1.30, unless I need her before. Daniel, it seems, is on his way.

Throughout the morning and into the afternoon I alternate between trying to help Paul with the nursery and lying on the bed with Gabe rubbing my back and tummy. When Marg arrives at 3.30 I still feel fine, but half an hour later the contractions are coming hard and fast. Marg and Paul assemble and fill the birthing pool while I labour on the lounge. My body tells me what to do and I find myself on all fours rocking back and forth and breathing heavily as each contraction peaks.

When I slide into the pool at 5.30 the relief is immediate. Gabe emerges from his bedroom wearing only his Speedos and jumps in beside me. After donning his goggles, he starts duck diving and performing all manner of underwater antics. When will Daniel be coming, he wants to know, and when will our secondary midwife

Mo arrive? Soon, Marg tells him, as a pretty big contraction hits and I move to all fours and start rocking again. I can hear myself panting and moaning while Gabe makes a whirlpool around me then pretends to be a dolphin.

After another fifteen minutes of this type of ‘assistance’, we persuade him to leave the pool for some Vegemite toast—things are getting serious and I need to concentrate.

By 6.15 the contractions are coming one on top of the other and they hurt a lot. Paul is beside me holding my hand. Marg is telling me I’m doing great. Gabe is eating toast, playing with silly putty and drawing pictures of Daniel’s birth as it unfolds. He doesn’t look the least bit perturbed until I let out a noise that sounds, I imagine, like the bellow of a dying cow or similar. I’m now in the zone, disappearing inside my head to escape the pain. I’ve read of other women doing this, but until this moment never believed it was really possible.

Marg calls Gabe to her side and I see his bottom lip quivering. But she puts her arm around him and tells him it’s okay. This is good pain, she explains, because it’s bringing Daniel to us. Between cow bellows I manage a smile and a wink. Gabe smiles back and joins Paul on the other side of the pool.

Then suddenly I feel it, that uncontrollable urge to push I've heard so much about, and Marg is telling me to reach down and feel for my baby. He's just inside me, the hardness of his little skull now only a finger length away. I shift to a squatting position. More pushing, more moaning. This is by far the most incredible thing I've ever experienced.

Is Daniel coming soon, I hear Gabe ask as he peers over the side of the pool. About another two or three pushes, Marg tells him before warning me I'll soon feel a burning or stinging sensation. For a moment I'm aware only of something rock-hard pressing down inside me, then I'm pushing again, as hard and for as long as I can. I hear myself scream and wonder for a moment if I'll be torn in half and whether it's really possible for Daniel to be born without major lasting damage to my vagina. Then I hear Marg tell Gabe to come and look at Daniel's head. On the next push, ease your baby out, she tells me. I think she must be mad—all I want to do is push like hell and can't imagine that easing is an option. But my body knows what to do and I find, to my utter amazement, that I can control the urge. I feel a small tear and hear Mo, who has just arrived, telling Gabe that the shoulders will come next. Then Marg is asking me to sit back on my haunches, bring Daniel up between my legs

and hold him to me. For a second I'm disoriented, but then I reach down and pull this tiny slippery form onto my chest. And there is my Daniel. He's chubby-cheeked and pink and coated in vernix. He is absolutely perfect. It is 6.50 pm.

Still connecting Daniel to my placenta, the umbilical cord floats in front of us continuing to pulsate. Daniel, I am saying softly, come on Daniel, Mummy's here. Paul too is calling Daniel's name, and tugging gently on his tiny foot. He is very pink now, his heartbeat strong, but when after some time he still has not breathed on his own, Marg uses the bag and mask to resuscitate him. After a few anxious moments there is a grimace. Then a gasp and a sputter. Finally his two little hands fly into the air and Daniel takes his first breath. I pull him closer and stroke his face as he lets out a soft cat-like cry.

Not compatible with life, they told us. But our little boy is here. And he is very much alive.

Minutes after breathing his first, Daniel is wrapped and cradled in his big brother's arms, while I await the contractions that will expel my placenta. Perched cross-legged in a bundle of cushions and blankets beside the pool, Gabe gazes down at the squirming

bundle on his lap and, rocking him gently, sings 'Morning Town Ride'. I know already that the image of their first moments together will remain with me forever.

When I too am settled in the little nest Marg has prepared for us, I remove Daniel's swaddling and lay him against my bare breast. I touch his face, kiss his head, inhale his newborn smell. Gabe is now snuggled on the pillow beside me, still staring at his brother, while crouched on my other side, Paul studies his new son's face, occasionally bending to kiss his cheek or stroke his skin.

In these first moments it is so easy to believe that the amniocentesis returned a false positive and that Daniel is a completely healthy baby. Only when I kiss the top of his head for the third or fourth time do I notice the gap in his skull. The size of a fifty-cent piece, it is covered by a thick membrane and is clean and dry. Aplasia, I will later recall—another common symptom of trisomy 13. Examining Daniel more closely we discover a previously undetected cleft palate but no other outward signs of his condition. Even the expected extra digit turns out to be just a tiny bubble of skin adjoining his left pinky.

When I am ready to relinquish my hold for a while, Daniel is weighed and measured. The scales are just inches from where I lay,

but the moment I let go of him I want him back. My longing for him is acute. When Mo returns him to me he is dressed, and snuggly wrapped in a pale blue bunny rug, his head now covered in a little yellow beanie Paul has dug from a box of Gabe's old baby clothes. It is one my mum knitted and is way too big but perfect for covering the aplasia without rubbing or snagging.

When Marg finally leaves us it is sometime after ten. The temperature has dropped to fourteen degrees—practically sub-arctic for us northerners—and Gabe is tucked up in our bed in his warmest PJs. Paul and I snuggle together on the lounge and prepare for our first night with Daniel. My decision to remain awake is not a conscious one, though perhaps on some level I am scared to waste a single moment. Or maybe I am just too elated to sleep. Paul dozes on and off, waking for the frequent nappy changes and to hold Daniel while I express milk into the small syringe for his feeds.

Then sometime after midnight Daniel opens his eyes and looks directly into mine. How to describe what I see in the newborn eyes of this child we were never supposed to meet? How to explain that for a few precious moments, undoubtedly the most profound and intimate of my life, the roles of my son and I are reversed, and that I am not the parent, but the child? In Daniel's eyes there is

knowledge, wisdom and acceptance beyond anything I have ever known. More than that, there is reassurance. Lowering my lips to his ear and speaking so softly that even Paul cannot hear, I reciprocate in the only way I can. I tell my son that I am here, that he will never be alone, and that if he has to go he will be in my arms when he does. I kiss his mouth and brush my tears from his cheek. Then Daniel turns his head to look at his dad.

Chapter 10

A lifetime

For a night and a day we lived in a self-contained bubble of love and complete happiness. Daniel slept, ate, squirmed and cried. His heartbeat remained strong, his breathing easy, and he was able to let us know in no uncertain terms when he needed a feed or a change. He was held only by loving hands, and never left the comfort and safety of our home. He knew, I believe, neither pain nor fear.

It was late Sunday night when Daniel suffered a short attack of apnea, an unforeseeable but potentially fatal symptom of trisomy 13.¹⁶ His breathing would stop for a second or two but resume as soon as I stroked his face or said his name. We phoned Marg who

came immediately, bringing oxygen. But by the time she arrived, Daniel's breathing had normalised. Though still a little restless, he was no longer hitching his breath and for the next couple of hours dozed on and off in my arms, fussing occasionally, but generally content.

My mum arrived on a late-night flight and by 1.30 was cradling her newest grandchild. She rocked him gently while he slept, whispering to him softly and humming familiar lullabies.

Just over an hour after first meeting his nana, Daniel's eyes opened and once more found mine. He had been sleeping on my lap while Mum and I chatted.

'Look, Mum,' I said, 'he's waking up.' But as I turned him to face her, Daniel squinted, his expression twisting into a deep grimace. For a split-second he looked like a Shar-pei puppy, his face a mass of crinkles and creases, then his tiny hands shot out before him, clenched and rigid.

'Daniel,' I said, already hearing the fear in my voice. 'Daniel, Mummy's here.' His eyes closed and his body relaxed, then Mum was at my side asking whether she should wake Paul. 'Not yet,' I said, before calling Daniel's name again, this time a little more loudly. Mum put her hand on mine.

‘Sweetheart, I think he’s gone.’ But I kept saying his name and talking to him softly. How could he be gone when just seconds ago he had been sleeping in my arms? I placed my head on his chest and heard his heart thumping, still as strong as ever. But I knew he was not breathing and when I looked at his eyelids I could see no movement beneath them. His face wore a calm expression, his little brow no longer furrowed. He looked completely at peace. When I felt Paul’s hand on my shoulder, the words bubbled from my mouth before I could stop them.

‘Do you want to try and resuscitate him?’ But he took my hand and shook his head.

‘No. We need to let him be.’ And he was right. I cannot explain how exactly I knew that it was more than just Daniel’s breathing that had stopped. I only know that the moment he died, despite my continued efforts to rouse him, I felt inside that he was gone. Later, after talking to doctors, I would realise that Daniel had suffered brainstem death—his brain could no longer send the messages his body needed to tell it to breathe, or regulate his blood pressure and temperature. And even though his little heart continued to pound in his chest, no amount of resuscitation could have brought him back.

Prior knowledge of Daniel's condition did not lessen the shock, or the pain. We had been so determined to prepare for a birth rather than a death that any anticipatory grieving was certainly done on a subconscious level. Daniel may have been a physical being for just thirty-two hours, but he had been a part of me for much longer. Nothing could have readied me for losing him.

In the weeks that followed, I sent many emails and letters telling of Daniel's short but precious life. I tried so hard to get it right, to somehow convey the depth of our love and the extent of our pride. I used lots of words like 'blessed' and 'privileged' and 'grateful'. All were inadequate.

A girlfriend later asked me whether the time we had with Daniel had flown, but in fact quite the opposite was true. Time had seemed almost to stop for us. I mentioned this to my dad during one of our many long phone conversations. It felt like so much longer than a day I told him.

'Well, Darlin,' he replied, 'for Daniel it was a lifetime.'

It sounds so very tragic that a life should be lived in just thirty-two hours, and yet I feel extraordinarily lucky. I had shared every moment of my child's life from conception to death and was able to protect him throughout, ensuring he

knew only love. Daniel died, safe and warm in my arms, my face the last thing he saw, my voice the last sound he heard. How many mothers have been so blessed?

Monday, July 9, 5.30 pm

The funeral director greets us politely and offers her condolences. We sit in a room with wallpapered walls and carpeted floors and cremation urns displayed on a stand in the corner. Daniel has been dead just fourteen-and-a-half hours.

She asks if we'd like her to take him now, and looks uncomfortable when Paul asks if we can hold him a while longer. It's better if I get him into the mortuary as soon as possible, she tells us. She hovers beside us as we kiss him goodbye then disappears into the back room taking Daniel with her.

When she returns, it's straight down to business. We try not to lose it as we explain our wishes for the funeral. It won't be held for another week, so we'd like to be able to visit Daniel beforehand. The funeral director shakes her head. She's sorry, but that won't be possible. We will not be able to see him again until he is delivered to us on the morning of his service. I do not ask why, but inside my head the alarm bells start to sound.

We tell her that we will hold the service at home and would like to accompany Daniel to the crematorium, remaining with him until the cremation takes place. I don't know that you really want to do that, she says. The crematorium is just a hot, dirty room and not a very nice place to farewell a loved one. Perhaps we would find it less traumatic if we did not attend. We agree to say our goodbyes at home, though the thought of Daniel being driven away by total strangers horrifies me.

I ask the director whether we will notice any changes in Daniel on the day of the funeral. It is very important to us that we be able to hold him and that Gabe be able to see his brother once more. Again she shakes her head. The bodies of newborn babies deteriorate very quickly; she can provide no guarantees about his physical condition. She offers no explanation as to why our son's body might continue to deteriorate when it is stored in supposedly ideal mortuary conditions, but suggests that his skin colour may have altered slightly and that he may give off a bad odour. Give me a call on the morning of the service, she says, I'll let you know how he looks then.

While I sit with my stomach churning, and clench my jaw so I do not scream, she keys figures into her desk calculator to tally the cost and leaves us twice to answer the phone in another room. At one

point she asks us how long Daniel lived. When I tell her thirty-two hours, she raises her eyebrows and I half expect her to throw me a wink. Well, she says, at least you got thirty-two hours. I stare at Paul and grip his hand. Is it just me, I'm asking him with my eyes, or is there something horribly wrong here?

Finally she reaches across the table and hands me two pieces of notepaper. The first is a roughly scribbled sequence of events:

8-8.30 AM DELIVER BABY TO HOME

11AM

SERVICE AT HOME

We Collect 2.00

Cremation 2.30 pm (UNATTENDED)

The second is an itemised quote. And we'll be needing that payment up front, she tells us as we stand to leave. It's standard practice. Perhaps she thinks it is the price that has so mortified me when I gape at her in disbelief.

Have you been in touch with Centrelink? she asks. They still pay the bonus even if your baby dies.

As she walks us to the door Paul turns and gives her a clumsy hug—a big hugger, my Paul, right now he would probably grab

the nearest telephone pole if nothing with a pulse was available. It takes all that's left of my waning resolve not to scone him with my handbag.

We need petrol, he says as we drive away. I don't want to leave Daniel with her, I say back. We drive to the servo in silence. Paul fills the car while I imagine Daniel's body decomposing. I stare at the floor so the other customers won't see me cry and jump when Paul opens the driver's side door. He looks at me for a minute then starts the car. Let's go back and get him, he says.

I call Information on my mobile and get the number for a second funeral service. I dial the number and a voice on the other end tells me we can bring Daniel right in.

Back so soon, says the funeral director as we enter the waiting room. Suddenly I am very conscious of my appearance. Paul has at least thrown on a collared shirt and some half-decent trousers. I am wearing baggy preggy daks, an oversized T-shirt and a pair of leather thongs. My hair is all afrizz—I haven't touched it since this morning. No wonder she advised us to contact Centrelink.

I'm sorry, I tell her, but we feel like we've made a mistake. We need to give this all some more thought and we want to take Daniel back. She casts us a knowing look. It's the money isn't it? No, we

assure her, it is not the money. Are you going with another company? she asks. Yes, I tell her. Yes, we are. She turns and leaves the room.

When she returns holding Daniel I can't help but smile. It seems so long since we've seen him but it has been no more than half an hour. I take a step towards them and lay the bunny rug I have brought on the desk. Still holding Daniel, the funeral director tells us she feels insulted. Her blood pressure, she says, has just 'gone through the roof'.

For a moment we just stand there, too stunned to respond. Finally Paul reaches for Daniel and I manage to clear my throat. Do we owe you anything, I ask—I want no reason to ever have to hear from this woman again. No, she says, but I hope you know how difficult this is for me. I'm sorry, I tell her as I help Paul with the bunny rug and start backtracking in the direction of the door, but I would have thought that since we lost our baby just a few hours ago maybe our feelings might take priority right now. She is still talking at us as we turn and leave the building.

I can't believe we left him there for even ten minutes, Paul says through gritted teeth as we drive away. As I hold Daniel closer, I can only cry and nod.

Chapter 11

A beautiful day

Monday, July 16

It is 7.15 am—one week, four hours and fifteen minutes since Daniel's death. I grip Paul's left hand as he steers with his right, and stare out the window at the passing cars. Drivers drum fingers on steering wheels, speak into mobile phones, apply make-up, sing along to tunes on the radio. It seems ludicrous that they should go about their daily lives while we make our way to the funeral home to collect our dead child.

The funeral director brings Daniel to us in a wheeled bassinette. I will always remember him there, his little blue jumpsuit clashing with the bright green blanket beneath him. He looks somehow smaller but still so very beautiful.

When I kiss his cheek it is cold and a little stiff but just as smooth as when we left him.

I carry Daniel from the funeral home swaddled in a blue and white bunny rug, and walking to the car wonder what passers-by must see. I am beaming down at my newborn baby as his proud dad, also smiling, opens the car door and helps us inside—a familiar scene straight from the maternity hospital carpark. Only the tiny white coffin tucked beneath Paul's arm betrays our true purpose. I do not place Daniel in his casket, but hold him in my arms, and as we drive along I am conscious of my hand beating a soft rhythm against his bottom as if to comfort him. And I realise that this is the most natural thing in the world. At three this afternoon we will drive Daniel to the crematorium and be physically separated from him forever. So today I will hold him and rock him and sing him lullabies. My baby is dead but he is still my baby.

When we pull into our drive Gabe's face appears at our bedroom window. He is not long out of bed, and still in his T-Rex PJs when he sprints down the hall to greet us. He strokes Daniel's forehead and kisses his cheek. How long can we have him, he wants to know. Just for the day, I tell him. Why can't we keep him forever? It's not the first time Gabe has asked me this but still I cannot find an answer

because inside I'm asking the same question, and I think that if someone told me right now that Daniel could somehow stay with us just as he is, even though it is only his body and not his soul, then that would be just fine with me.

I undress Daniel just after ten. I wash him and change his singlet and nappy, grateful that it is my hands performing these final intimate acts. We have picked out a cream-coloured outfit and my mum has knitted a beanie to match. But the suit is so big and the colour all wrong, so I dress him once more in his little blue teddy bear jumpsuit and hat.

I await the inevitable outbreak of tears and am surprised when it does not come. I so want this to be a day of celebration and it seems my emotions are right there with me.

Marg, Mo and Pastor Lester arrive just before eleven and we gather beneath the yellow flame tree in our backyard for some prayers and songs to commemorate Daniel's life. The decision to exclude even our closest friends from the service was a difficult one, but as we take our seats in the shade, our pet beagle Salman sniffing at our feet, there is a feeling of rightness to the gathering. The service itself is short and simple, though every word has been carefully chosen.

So many memories of this day will remain with me forever, but perhaps the most precious will be of Gabe's hand on my shoulder as he sings along to 'Danny Boy'.

Time seems to slow for us once more as we spend our final hours with Daniel. But still the moment to go comes too soon. When each of us has held and rocked him one last time, Paul brings the casket from the car and places it on our bed. As small as he is, Daniel nearly fills it up. Beside him there is room only for Peter Rabbit—Gabe's favourite soft toy—and a copy of the poem Paul has written for him. It does not pain me to see him lying there on the casket's satiny lining with its pretty lace trim. He still looks just like he is sleeping.

We leave the casket open on the ride to the crematorium and as I stare at Daniel's face, taking in every detail one last time, I can feel my mind taking me someplace else. When the time comes to place the lid on the casket, I do it like it's the easiest thing in the world. We carry him inside the little chapel and lay him on the table in the designated area. There are curtains all around us and, when we are ready, we will step away and they will close.

For a long time I stand with my hands on the casket, not able to leave him. But I know I will never be ready and I cannot stand here

forever. Finally I take a seat on the front pew beside Gabe who is crying a little, and Paul tells the attendant we are ready. He draws the curtains and we stand and walk away.

We are halfway home when the panic hits and I want more than anything to tell Paul to turn the car around. But I know that by now my baby boy will be no more. It's easy to shut my mind to reality—the feeling of Daniel's weight in my arms is still so fresh. So I close my eyes and think only of the way he looked in his little blue suit and his matching hat with the teddy bear ears.

And I thank God for giving us one last beautiful day.

Chapter 12

Afterwards

No one tells you that when your baby dies your body will remain in denial long after your mind has begun to accept. That you will find yourself rocking slowly from side to side and humming lullabies aloud while you wait at the checkout or put petrol in the car. That your breasts will gush each time you look at a photo or cry for your dead child. That your hands will continue to reach for your belly although it no longer bulges with life. That your empty womb and vacant arms will feel awkward and foreign. That sometimes all these things will go on, not for weeks, but for months.

Daniel has been gone fifteen weeks today, and I wonder when I'll ever stop counting. My stitches have long dissolved, my milk has dried up, I'm only a kilo and a bit off my pre-pregnancy weight, and I haven't had that panicky 'forgot-to-check-the-baby' feeling for at least a month now.

More than once I've jumped the unavoidable hurdle of being asked how and where my baby is, and each time have landed safely on the other side. Everywhere I go now I carry a small photo album filled with pictures of Daniel, and pull it out at every opportunity to show it to anyone who'll stop long enough to look. Sometimes I wonder whether there's pleading in my eyes when I ask them if they'd like to see, but I've never much cared what others think of how I'm 'handling' myself.

The remembrance garden my mum helped us to make is growing nicely and some of its flowers have already started to bloom. We've called it 'Gabe and Daniel's Garden' so Gabe will not feel less special or less deserving than his brother. It's beneath our big yellow flame tree, with stepping stones leading to a little concrete bench so we can sit there in the shade.

Daniel's room is just as he left it. After dark we light a candle in his window and most nights I find myself cradling my favourite

photograph of him and singing it a lullaby before I go to bed. A disturbing image for some, I'm sure, though I expect most mothers will understand my need. When will I stop? I don't know. Maybe on Daniel's first birthday or when he turns two, for that was when Gabe became too big to rock in my arms. Or maybe I will do it forever.

I have not yet dreamed of Daniel, or encountered any of the signs I've heard many grieving mothers speak of. I do not have any sense of him trying to communicate with me, to take away my grief or to reassure me that I loved him enough—that he did already, on the night he was born, with just one look. Sometimes though, when I am home alone, I go into his room. It smells like dried flowers and faintly of Lux™ soap flakes and there is always a warm breeze blowing through the open louvres. Some days I touch the softness of the neatly folded baby clothes beneath the change table, or rearrange the stuffed animals on top of the toy box. Mostly I just stand at the foot of the cot and look around at all the things he would have touched and loved. And it is then I feel closest to finding some kind of peace.

Grief, I'm discovering, is not a finite process. I will not get over Daniel as I would a bad cold, or move on from him as I would an

old boyfriend. Do I feel him in a spiritual sense? I think I still crave his physical presence far too much, though he is with me in a way I could never articulate. Certainly not more beautifully or aptly than grieving mother Judi Walker in the words she wrote in memory of her murdered son Shane.

*... Don't tell me it is time to move on,
Because I cannot,
Don't tell me to face the fact he is gone,
Because denial is something I can't stop,
Don't tell me to be thankful for the time I had,
Because I wanted more,
Don't tell me when I am my old self you will be glad,
I'll never be as I was before ...*¹⁷

Sometimes I try to step outside myself and look at the person I've become. The changes aren't something you can see in the mirror—apart from the residual muffin-top and a bit of additional cellulite, the woman I see looks pretty much the same as she did twelve-months-ago. The grief is not etched on my face; there is no ghost in my eyes. But I know things I could never have learned

without Daniel. I know what it is to have people glance at my almost-flat stomach, frown at my empty arms and look around expectantly for a pram or a nappy bag. And I know I would prefer an awkwardly mumbled ‘I’m sorry’ or a hurriedly blurted ‘condolences’ to the pretence that Daniel never existed at all.

I know that people are essentially good—that non-judgmental and unconditional friendship and love are the only kinds worth having; that life is precious, no matter how fleeting; that *all* babies are beautiful. And I know that a mother who has lost her child, even if it never breathed outside her womb, is no less proud, no less loving, no less a mother.

To this day, I have not felt the need to ask ‘why me?’, though the broader question of why trisomies occur at all is never far from my mind. Parents of trisomy babies are constantly reassured that errors in chromosome division are common and beyond their control, a point stressed by the authors of *Trisomy 13: a Handbook for Families*:

There is no scientific evidence to suggest that exposure to environmental dangers or X-rays, living an unhealthy life-style, drinking, smoking, drug use, stress or poor parental health can

cause trisomy 13. It is important to remember that nothing either parent did or failed to do could have caused or prevented the presence of the extra chromosome 13.¹⁸

This may well be true, but just how much effort has been expended to research possible causes of a condition that statistics suggest is found in only one in 7,500–10,000 live births?¹⁹

I know that the decision to undergo prenatal testing, particularly invasive procedures, is one no parent should take lightly, and that no pregnant woman should be expected to consent unless she has been fully advised of all the risks and potential complications.

Never again will I conceive a child fearlessly, or be blissfully ignorant of what *could* go wrong. Yet I have gained a new appreciation for the value of prenatal ultrasound and amniocentesis. While I once viewed these procedures as scary and suspicious, I am so thankful we knew of Daniel's condition in advance. It's true that he would have died regardless, but prenatal diagnosis allowed us to make truly informed decisions, something that would not have been possible amidst the shock and panic of discovering his condition at birth.

I know that available support for parents who receive a poor prenatal diagnosis is grossly inadequate. While individual medical professionals may be compassionate and well-informed, the broader medical fraternity places babies like Daniel and parents like us in the too-hard basket, and promotes termination as the only valid ‘solution.’ I know also that I would be happy to never again hear the words ‘not compatible with life.’ I don’t suggest for a minute that doctors should lie to parents of babies with potentially life-threatening disorders, or even try to soften the blow. Tell us our children have severe conditions. Tell us their lives are at risk. Tell us there is nothing you can do. But do not tell us that they *cannot* live or that there is nothing *anyone* can do unless you are 100% sure that is true. And never tell us that our babies’ lives will not be worth living because they may last only seconds, minutes or hours. That is not your decision to make.

I know that sometimes the most perfect words are also the simplest ones. A week after Daniel’s death we found a brown paper bag in our letterbox. It was full of cards that the kids from Gabe’s class had made. My favourite was from a little girl called Chloe who wrote, ‘To Gabe, Im sorry to hear your baby dide.’

I’m infinitely grateful that I know *all* these things.

So if you see me, don't look the other way or cross the street so we don't have to meet. Ask me about my baby. Ask who he looked like and whether his eyes were black like his brother's or green like his dad's. Ask how much hair he had and how loud he cried and whether his skin was fair or dark. Ask me about his weight and his length and the size of his head. Let me show you his photo and tell you about his life, because I remember every bit of it.

It's true—I will never be as I was before. Nor will I ever want to be. Daniel was worth all this pain and more, and if I had it to do over, I would change nothing. People tell me that I'm brave, that what Paul and I chose to do was amazing, but I don't see it that way. For me, there really was no choice. Daniel was my child. I carried him, I gave birth to him, I loved him.

It was the easiest thing in the world.

Acknowledgements

I truly believe that I was meant to be Daniel's mum, and that I would have carried him and brought him into the world no matter what. Without the love and support of those close to me, the journey would have been so much lonelier. To all those who've walked beside me, thank you.

A note to parents

If you have recently been advised that your unborn child may have a potentially life-threatening condition, chances are you are currently experiencing a range of responses and emotions including confusion, disbelief, anger, denial and grief. You may have been told that your baby will die *in-utero*, during labour, or very shortly after birth, or that survival will mean a life of profound disability and suffering.

If your baby has a chromosomal disorder like trisomy 13, you will almost certainly have been told that the condition is 'not compatible with life' and 'inappropriate to treat', or that your baby is 'genetically programmed not to live'. Your doctors have probably informed you that most parents in your position choose to end their baby's life and, in some cases, they may even have pressured you to terminate your pregnancy.

Immediately following this devastating news, you may have been asked to make choices based on information that is outdated, incomplete, or grossly inaccurate. If this is the case,

help is available. Access to current and accurate material and contact with others who have travelled a similar path can alleviate much of the confusion and loneliness you are experiencing, and empower you to make informed decisions for your baby.

On the following pages, you will find a condensed version of an information pack I compiled during my pregnancy. Please read the explanations and view the recommended resources. Most importantly, don't be afraid to keep asking questions until you are satisfied with the answers you receive.

DETECTION—MARKERS AND WHAT THEY MIGHT MEAN

For many families, the initial signs that something is wrong are detected during a routine prenatal ultrasound or foetal anomaly scan at around the sixteen- to twenty-week mark. These signs are commonly referred to as 'markers'. Simply defined, ultrasound markers are deviations from the normal anatomy seen on an ultrasound scan. In isolation, they are often of no significance and can appear in perfectly healthy babies. Occasionally, and more particularly if multiple markers are found, their presence may indicate an underlying chromosomal abnormality or the presence of a similarly serious syndrome.

Having detected multiple markers, your ultrasound operator will most likely seek a second opinion, contact your obstetrician, and schedule a more detailed scan. Further diagnostic testing in the form of amniocentesis may also be offered to you at this point.

The period of uncertainty following initial detection is extremely painful and traumatic, but it is important to remember that, while prenatal ultrasound can detect specific anomalies, it CANNOT provide a definitive diagnosis of your baby's condition. Nor is it possible at this stage in your pregnancy to predict how some internal organs will develop. Problems that initially appear to be significant may become increasingly less so, or disappear completely as your baby continues to grow.

For these reasons, no decision about your baby's future should be based on the results of initial ultrasound findings alone.

FURTHER DIAGNOSTIC TESTING—MAKING THE RIGHT DECISION FOR YOU AND YOUR BABY

Proceeding with amniocentesis is an obvious choice for some parents, while others find the decision extremely difficult. The procedure carries a number of risks, most notably a 1-in-200

chance of miscarriage. Other potential complications include vaginal bleeding, amniotic fluid leakage, and infection. If it is suspected that your baby might have a chromosomal condition, your doctors may warn of an increased likelihood of miscarriage following amniocentesis ‘because so many babies with these conditions are likely to spontaneously abort anyway.’ At this point, you may wish to consider what exactly you hope to gain from agreeing to undergo amniocentesis, and whether you are prepared for the further choices you will face should the procedure return a diagnosis of trisomy 13 or similar.

Where a trisomy is suspected at this stage of pregnancy, a definite diagnosis by amniocentesis may:

- allow expectant parents the option to end the pregnancy; or
- assist parents and their doctors in managing the pregnancy, and allow them to plan the birth most appropriate to the baby’s individual needs, ensuring the availability of adequate support facilities and specialised medical staff; and

- influence the obstetrics team's advice in terms of how the baby should be delivered.

While knowing there are sound reasons to justify amniocentesis does not necessarily make the decision to proceed any easier; ensuring you have all the available facts will at least allow you to make an informed decision.

DIAGNOSIS: TRISOMY 13—WHAT NOW?

Assuming your amniocentesis returned a positive diagnosis for trisomy 13 or a similar disorder, you will most likely be offered the option to terminate your pregnancy.

At this point it is essential that you have access to current and accurate information. Request to see written reports of all test results and have your medical professional explain what they mean.

Questions you may wish to ask your practitioner include:

- What form of trisomy 13 does my baby have (full, mosaic, partial, translocation), and what exactly does this mean?

- What are my baby’s specific anomalies?
- I would like to seek further advice and undergo further diagnostic testing before making my decision—can you refer me to the appropriate specialists?
- Are you aware that a number of trisomy 13 (or similar disorder) babies do survive, and that there are children and adults living with the condition today?
- What exactly will termination entail?
- Can you explain the actual procedure?
- What medications will I need to take, and what are their known side effects?
- What are the potential complications, and what risks do they present to my future health and fertility?

- What will my baby experience?
- Who will be present during the procedure?
- Will I have access to counselling before and after the procedure, and can you recommend any support organisations?

Whether or not to continue your pregnancy following a poor prenatal diagnosis is an extremely personal decision, and no one has the right to judge another's chosen course. This guide simply aims to help you gather the necessary information to ensure you understand the implications of whichever path you choose. After hearing your medical practitioner's views, it may be worth considering other perspectives. For links to articles and personal accounts, see: www.livingwithtrisomy13.org/trisomy-13-termination.htm, and www.dipex.org/endingapregnancy.

CONTINUING WITH YOUR PREGNANCY

You are no doubt aware that there are many more decisions ahead. The road will be long and at times very tough. If you are fortunate enough to have found compassionate, open-minded, and well-informed physicians, you are off to a great start. Sadly, this is not always the case. Regardless of whether you are considering comfort measures alone or plan to pursue extensive medical treatment for your child, it is essential to have a thorough knowledge of your options for pregnancy management, labour and delivery, and postnatal care.

Pre-armed with the information contained in the following books, articles and web sites, you will be well equipped to discuss these issues with your medical team and, if necessary, provide evidence to counter the standard blanket prognoses of ‘not compatible with life’ and ‘inappropriate to treat’. The resources I’ve listed were of great use to me during my time with Daniel. I hope they will help make your own journey a little easier.

HELPFUL RESOURCES

Prenatal testing

Beryl R Benacerraf, MD. 'The sonographic diagnosis of fetal aneuploidy'

www.patients.uptodate.com/topic.asp?file=antenatl/4468

Sarah J Buckley. 'Prenatal Testing and Screening'

www.bellybelly.com.au/articles/pregnancy/pre-natal-testing

Sarah J Buckley. 'Ultrasound scans – a cause for concern'

www.sarahjbuckley.com/articles/ultrasound-scans.htm

Alessandro Ghidini, MD. 'Patient information: Amniocentesis'

www.patients.uptodate.com/topic.asp?file=pregnan/6937

Wendy Hogarth. 'Amniocentesis: The Struggle to Choose'

www.humanehealthcare.com/Article.asp?art_id=755

Monica Rafie (founder and administrator of BeNotAfraid.Net). 'A Different Kind of Crisis Pregnancy: When There is "Bad News" About Baby'.
www.humanlife.net/view_reports.htm?rpId=23

Robert G Resta. 'Genetic Counseling: Coping with the Human Impact of Genetic Disease'.
www.accessexcellence.org/AE/AEC/CC/counseling_background.html

Elizabeth Steine, CNM. 'Should I have an amniocentesis?'.
www.askyourmidwife.com/amniocentesis.html

'What are chromosomal abnormalities?'.
www.babycenter.com.au/pregnancy/antenatalhealth/scans/ultrasoundmarkers

Prenatal Support

www.BeNotAfraid.net

www.emmanuelfoundation.org

www.LivingWithTrisomy13.org

Amy Kuebelbeck. *Waiting with Gabriel*. Loyola Press, Chicago, 2003.

www.michaelsfeat.org

www.perinatalhospice.org/More_resources.html

www.prenatalpartnersforlife.com

Trisomy 13 Information

www.hopefortrisomy13and18.org

www.LivingWithTrisomy13.org

Rainbows Down Under—

<http://members.optushome.com.au/karens/>

www.trisomyonline.org

www.trisomy.org

Birth Choices

www.babycenter.com.au

www.bellybelly.com.au

www.naturalbirth.org.au

www.sarahjbuckley.com

www.sheilakitzyinger.com

Loss of a Baby

www.cradle.org.au

Hannah Lothrop. *Help, Comfort and Hope After Losing Your Baby in Pregnancy or the First Year.* Element Books Limited, Shaftesbury, 1999.

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www.sands.org.au

www.sidsandkids.org

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Please visit <http://www.babycenter.com.au/> for more information.

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The sonographer stops. He is seeing some things that don't look quite right: 'markers' commonly indicative of a chromosomal disorder.

'Is it Down syndrome?'

'No, the disorders we're talking now generally have far graver outcomes.'

'I'm sorry,' I stammer, 'I'm not sure what that means.'

'These disorders are "not compatible with life" —the baby will probably die in-utero or very shortly after birth. Many people whose babies are diagnosed with these conditions choose to end the pregnancy.'

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