A photograph of a woman in a white t-shirt and light blue jeans supporting a toddler in a blue shirt and tan pants against a white wall. The toddler is wearing a cast on their right leg. The wall has a window with a red frame and a small vent. The ground is asphalt with some dry leaves.

# Finding a new normal

When NEW MAMA *Melanie Dimmitt* was told her precious bebe had CEREBRAL PALSY, she had to RE-IMAGINE his (and her) future.

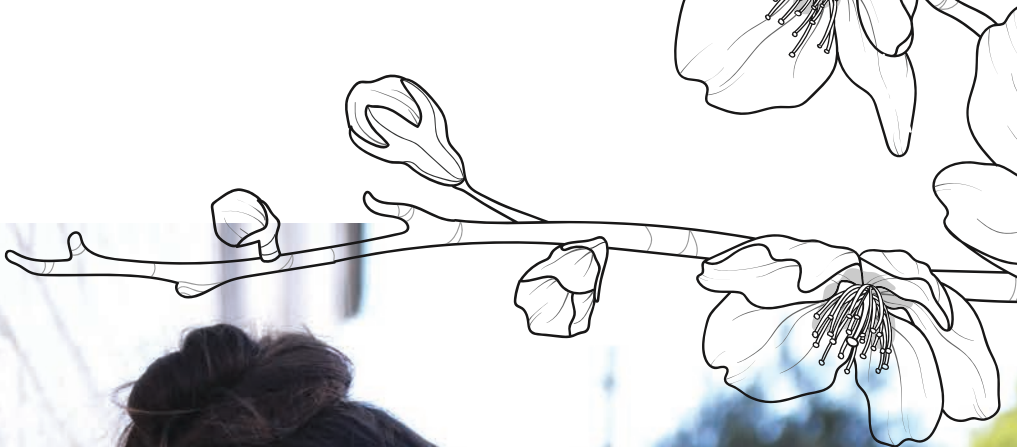


**W**hen I emerged from the general anaesthesia of Arlo's emergency caesarean, I asked the surgeon two questions. One: "Is he alive?". The surgeon smiled and said, "Yes". Two: "Does he have Down syndrome?"

My concern wasn't entirely random. According to the results of our 12-week scan, this baby had a slightly higher risk of having the most common of chromosome disorders. Rowan and I had been quietly crapping ourselves over this possibility for the preceding six months. The surgeon answered, "No". Well heck yes, I thought.

But what that surgeon must have known (and mercifully not mentioned) during my heavily drugged interrogation was that we weren't out of the woods. *Au contraire*. We were going to have to roll up our sleeves, build ourselves a cabin and shack up forever in the woods. You don't go a full ten minutes without oxygen and come out scot-free. So after six months of blissfully tending to our stiff-limbed little lad, Arlo was diagnosed with cerebral palsy.






“I’ll bet you’re worrying about everything there is to worry about, but you know what? It will all be fine.” These were the unsolicited two-cents-worth thrown in by a woman situated beside me as I pregnantly puffed through a yoga class. Well, lady, it wasn’t. But we sure do take for granted that pregnancies at a well-rounded point of conspicuousness will end with a standard-issue kid. Of course we do. Babies are marketed to us as neat, knowable packages tied in bows of candy pink and duck-egg blue.

There wasn’t any mention of “disability” in our birthing classes (but lots of birth planning, which came in really handy for my emergency caesarean section), despite one of the couples in our batch already knowing their child had a clubfoot. The well-known guide *What to Expect When You’re Expecting* assumes we’re all having a typically developing child, while Robin Barker’s *Baby Love*, a 630-page tome covering ‘Everything you need to know about your new baby’, according to its tagline, sports a stingy, four-and-a-half-line paragraph under the heading ‘Babies Born With Problems’.

Online parenting platforms are more concerned with popular baby names than potential birth defects, while the general lack of representation of disabled communities across mainstream media blinds us to the possibility of ever birthing a future member. So, due in large part to a society that shows us an extremely narrow snap-shot of how things actually are (fact: almost one in five Australians are currently going about their day with their particular disability), most parents are only prepared for a ‘perfect’ specimen.



To celebrate Arlo’s future, Melanie had to let go of the dreams she had held for him.



## A LIFE LESS ORDINARY



“You have a world of dreams around your child. You can’t help it. And when you’re told ‘No, that’s not going to happen,’ it’s really hard to adjust.”

“You have a world of dreams around your child. You’re imagining their future – you can’t help it, that’s what you do – and when you’re told ‘No, that’s not going to happen,’ it’s really hard to adjust,” says Jocelyn Moorhouse, one of the first mothers I met in the special-needs sphere. She and her husband, P. J. Hogan, are filmmakers, behind titles including *Muriel’s Wedding* and *My Best Friend’s Wedding*. They have four children, two of whom Jocelyn affectionately calls her ‘autistic darlings’. I first interviewed Jocelyn for a magazine article amid the buzz surrounding her directorial comeback, after a lengthy hiatus, by way of box-office smash *The Dressmaker*. It comforted me to discover that parenting a child with special needs – two, in Jocelyn’s case – need not kill one’s career. After keeping my professionalism intact until our sign-off, having only recently received Arlo’s diagnosis, I blurted something along the lines of, “You’re such an inspiration!” (a sentiment I would later learn irks more parents than not). Jocelyn took the time to console me and, a few months later, speak to me again from her Sydney home.

“It’s exhausting, isn’t it? In the beginning – especially the first few years,” she says, above the whir of her washing machine (‘it’s towels and sheets day’). “You’re going along having a so-called normal life and then, all of a sudden, you’re not.”

Jocelyn and P. J. were living in LA when they noticed their second

child, daughter Lily, wasn’t behaving like other two-year-olds. Lily was diagnosed with autism, as was their third child, Jack. “Part of you goes, ‘It’s not fair! I wasn’t ready for this, I didn’t sign up for this!’,” says Jocelyn. “But of course, no one signs up for this ... and we had to go through a stage of grieving. It’s grieving for what you imagined your future was going to be. That’s all it is. You’re not grieving the child – they’re still with you – you’re just grieving your dreams. You have to build new ones. And you will. You will build new ones.”

Exciting ones, according to Michelle Sullivan, whose Littlest Warrior Apparel business was inspired by her son Eli, who has Down syndrome. “I had to grieve the life I had already dreamt up in my mind for my first boy,” she says. “I had no idea what joy and adventure was waiting for us. Knowing what I now know, I so wish I could go back and give myself a glimpse of what our lives are like now. Yes, our lives are different, but so much better. There is so much more joy, and love and hope.”

While waiting on those new dreams and milestones to emerge, however, many parents suffered the slow and painful deaths of their old ones – and Australian television presenter and model Chloe Maxwell, who you might remember as the ‘Jeanswest Girl’, is one such parent.

“I have no agenda other than their highest wellbeing. That’s the only thing I’m looking out for.”

Up until her son, Max, was diagnosed with autism, Chloe was very exacting in her designs for this three-year-old. “I guess I was most fearful, selfishly, of him not living up to the dreams and expectations I had for him,” she tells me. “I wanted to see Max get married and achieve things in life. I wanted to experience these milestones with him and I didn’t see that coming to fruition ... I was also worried he would struggle to make friends and enjoy his life the way I had imagined he would.”

Much of our struggle as a parent is self-inflicted, because we’ve projected all of our stuff on to this tiny soul. Our aspirations. Our insecurities. Our non-negotiables. Our need to continue ‘our legacy’. We formulate an entirely fictional being in our brains that neither was, is, or ever would have been.

The good news, for those of us in special scenarios, is you can farewell this impostor much sooner than you otherwise might have. But it is a sad goodbye.

“It’s a shame in a way that there are certain things that, regardless of whether he’s interested, he’ll never get to experience,” remarks my partner, Rowan, as we chat about Arlo one evening. “There will be things that he would enjoy but he’s not able to because of a nuts-and-bolts issue.”

Washing machine still whirring, Jocelyn assures me that the longer you live with your child and who they are, the less you remember your imaginary version of them.

“You do adjust,” she says, “and it’s not necessarily a bad thing, because you get to see who they really are. Who do I have here? Who are you, little guy? And once you figure that one out, it does make you a better parent.”

It’s only when our plans fall through, and a situation fails to conform to our expectations, that there’s this potential for our own growth.

Meeting your child’s needs – special as they are – will become second nature. But, if you ever find yourself at a loss, cast your thoughts to the indomitable genius of Oprah. While chatting to Gwyneth Paltrow on *The Goop* podcast, when it came to the subject of parenting her adopted children, she remarked: “I have no agenda other than [their] highest wellbeing ... That’s the only thing I’m looking out for.”

You probably wouldn’t have chosen this journey, but hang tight. Time and time again parents told me they’ve found beauty in life’s challenges. Knowing what they know now, feeling what they feel now, they wouldn’t change how they have it for the world. <sup>MD</sup>



This is an extract from *Special* by Melanie Dimmitt, Ventura Press, RRP\$32.99

