

Chapter 1: Departure

Fitting four people, five giant suitcases and a wheelchair into a small four-wheel drive isn't easy. OK, we have four giant suitcases and one case just slightly smaller. But there are two carry-ons as well, and they're as big as aeroplane carry-ons are allowed to be. Anyway you look at it, by the time we get all those cases, the wheelchair and four bodies into the car, we're sandwiched in pretty damned tight.

The drive to Melbourne airport is uneventful, except that the small giant, which is balanced on the back seat, keeps tipping onto Val, my wife, or the other way onto Nathan, my 17-year-old disabled son. I'm driving carefully because I don't want the small giant to tip onto Val, who'll give it to me, or onto Nathan, who can't lift his arms to protect himself, and because I don't want to have to brake suddenly and cause the top suitcase in the back to shoot forward and bang Val in the back of the head. Otherwise, it's a smooth trip, about 90 minutes, but for some reason Nathan starts getting agitated.

At the airport we have a brief argument about where to park, but there's no heat in it. We are, after all, going on a holiday for three weeks; first four days in Fiji, two days in L.A. then two weeks in Costa Rica for a wedding. We park the car in a disabled parking bay where Jane is sure she'll be able to find it for her drive home.

In the short walk from the car to the airport, Nathan lets us know he is not happy. He never complains unless something is hurting, and he is complaining now. So, we don't go to the check-in first; we leave Jane with the suitcases at McDonalds and take Nathan to the parenting room to work out what is bothering him. There's a couch in there, so we're able to get him out of his wheelchair and onto the couch and search for the source of his discomfort. It's easy to find, we think.

Nathan is wearing a condom catheter, a condom with a tube that leads to a bag strapped to his leg. We haven't been using these things for long. We found out about them about a month ago, when we were looking for solutions to Nathan's unique, long distance travel problems. The problem seems to be that the condom, which is made of sticky, clingy plastic, has caught hold of some hair in that oh so sensitive place, and is pulling them hard. Ouch!

'How do we get it off?' I ask, fiddling fruitlessly with my son's abused appendage.

'Just rip it off,' says Val. 'One sudden tug.'

So, I tug, suddenly and hard, and Nathan, who is totally incapable of voluntary or controlled movement, nearly lifts off the couch. The condom holds on grimly. Bad move. My poor kid.

There's no other way but to claw, ease and bully the bloody thing off, though it brings a good tuft of Nathan's pubic hair with it. Now he's not just complaining, he's wailing.

We settle him as best we can, apologising profusely and wringing our hands at our clumsiness. Then we get him into his chair and go back to where Jane is waiting patiently at McDonalds amid our pile of luggage.

'He needs Panadol,' says Val as she delves into her handbag, 'and I need...' She turns to me. 'Go and ask for a cup of hot water and a cup of cold water.' She gestures with her head towards the McDonalds counter. This is a chore she won't do herself, and she knows that I, like her, hate asking sales staff for change, directions or anything that's not to do with them making a sale. So, she won't look at me as she throws me these orders, because she knows I'm going to be ticked. But I can't make a fuss now, my kid needs these things. I go to the McDonalds counter and get hot and cold water.

Nathan gets all his drugs, some of his food and most of his fluids through a peg in his belly. Val gives him the Panadol using a feeder tub and a syringe, and Nathan promptly throws up all over Val, Jane and himself.

There's a guy right by us in McDonalds, eating a Big Mac. He does his best to ignore us, but God knows what he's thinking.

We take Nathan back to the parenting room and discuss what to do. Not getting onto the plane is a possibility that haunts both our minds, but neither of us mentions it.

‘It obviously wasn’t the condom,’ says Val.

‘Could have been,’ I reply. ‘That part of the body, it’s so sensitive, any kind of hurt there can make you nauseous.’ I can say stupid things sometimes. When I was a kid, I got hit in the nuts by a rock in a slingshot fight with some mates, and I’m remembering that pain and the accompanying nausea as I offer this ridiculous explanation. But Val is as desperate as I am to find a solution. She accepts what I say and we decide not to abuse Nathan’s penis with another condom, and to rely on his nappy until we get to Fiji.

We go back out into the real world with a thin veneer of hope that we’ve found the right solution. Jane tells us the guy eating the Big Mac in McDonalds had wished us good luck.

We head to a bar, for a farewell drink and to kill some time. We order three glasses of champagne, but we’ve hardly touched them before Nathan throws up again.

Back to the parenting room for another clean-up and a search for answers. As I’m getting Nathan out of his chair someone starts banging on the door. Val goes to the door and talks to an irate cleaner who wants to come in, and wants us out so she can do her job. She has to wait. She’s not happy about it, but our ability to be sympathetic to the needs of others is low right now.

We realize now that the condom was not what was bothering Nathan, and we’ve got a significant problem. His eyes are glazed, but it’s the nasty cough he’s developing that really worries us.

A cough – so what? Nothing deadly about a cough.

Well, not usually. But Nathan only has one functioning lung; and we were told in his early years that the biggest threat to his well-being would be chest infections and lung problems. And here we are about to embark on a five-hour plane trip, with reduced oxygen levels, and our boy has a chesty cough that’s bringing awful green stuff from deep in his lungs. Yeah, we have reason to worry.

Our stress levels are rising, and even though we're going, we hope, on the most ambitious holiday we've had since Nathan was born, we start to bicker, and this time there's heat in it.

We rejoin Jane and our pile of luggage. 'Should we get on the plane?' Val asks.

'Don't be bloody silly,' says Jane. 'You can get to Fiji and then see how he's doing.'

Jane is down-to-earth sensible. She has been one of Nathan's carers for a long time. She knows him almost as well as we do, and her conviction reassures us.

There is still quite a wait before our departure, and we spend most of it in line, studying Nathan for clues that will tell us how he's feeling. Val and I want to be happy about our impending holiday, but, given Nathan's uncertain state, being happy is hard.

Somewhere round midnight, Nathan dozes. Nathan is non-verbal. His larynx works OK, he can make noises, but we have to judge what he's trying to say by the tone of his voice more than by the sounds, and by the expression on his face. Over the years we've learnt to read those expressions. A smile means yes – and, by the way, my boy has got the world's best smile. It lights up his whole face and it causes everybody around him to smile with him. A deadpan expression means no. An *I-just-sucked-on-a-lemon* face means something is hurting. But he's asleep now, there's no point in trying to read how he's feeling; so, it's settled, we're going.

As always, we get to board first. To get Nathan from his wheelchair to his seat in the plane I have to carry him from aircraft door to seat, and every time we have the same argument with airline officials. It goes something like this:

Airline official: Sir, would you like an aisle wheelchair?

Me: No thanks, I'll carry him.

Airline official: No sir, we can't allow you to carry him onto the plane. It's a safety thing. It's for your own protection.

Me: I can't lift him out of the aisle wheelchair, it's too low and the aisle is too narrow.

Airline official: Sir, we can't allow you to carry him onto the plane. It's a safety thing.

Me: I can't lift him out of the aisle wheelchair, it's too low and the space is too narrow.

I could go on for the next ten lines and repeat the above statements over and over. This time, the airline official, a very attractive lady, who under normal circumstances could get me eating out of the palm of her hand, is unmovingly stubborn. She is not going to let me carry Nathan onto the plane.

This upsets me, but it upsets Val more. I am upset because giving in means we are going to put Nathan in the aisle wheelchair, take him to our seats, find that we cannot get Nathan out of the aisle wheelchair unless some of the seats are unbolted and removed. We will then take Nathan back to the entrance to the plane, I will lift him and carry him to the seat, which is what I wanted to do in the first place. Val is upset because the whole rigmarole of trying to lift Nathan out of the aisle wheelchair requires some manipulation of him, always unsuccessfully, by well-meaning airline staff who have no experience in handling a disabled kid. She sees it as an affront to his personal dignity. Val is big on Nathan's personal dignity.

Val tries one more time. 'Have you ever tried lifting a disabled child out of a wheelchair?' she asks. I like her *you've never walked in my shoes* strategy, but it cuts no mustard with the pretty but stubborn airline staffer.

'No ma'am,' she says, 'you have my sympathies,' – that's a line that pisses us both off, we're not looking for anyone's sympathy – 'but I simply can't let you carry your son onto the plane. It's a safety thing.'

We give in. But we don't give up, we know we're going to win in the end, and I am hoping that Pretty But Stubborn is there when that happens. We lift Nathan out of his chair and into the aisle chair, then proceed down the air-bridge and into the aircraft. We're pleased to see that Pretty But Stubborn comes with us. We take Nathan the short distance to our seats. We always ask for the bulkhead seats, because they offer more room for getting Nathan into and out of his seat, but even with the

extra room we hit the standard problem: there is not enough room to stand beside the aisle wheelchair to lift Nathan out.

We look at Pretty But Stubborn to make sure she's paying attention. 'Can you lift him?' Val asks me, though she knows the answer.

'No,' I say, 'there's not enough room for me to position my feet to protect my back.'

'Can't you try?' asks Pretty But Stubborn.

'But you said using this aisle chair was a safety thing,' I argue. 'How can it be a safety thing if it risks my back?'

'I'll get you some help,' she says, and I know we're coming to the part that both Val and I really, really hate.

Pretty But Stubborn goes away, and returns with a big and burly bloke and a smug smile on her face. 'This is Phillip,' she says. 'Phillip can help you lift.'

I shake Phillip's hand, say all the right things about thanks for the help, and we've got to protect Nathan's back because he has a rod in his spine. And then together we try to lift Nathan out of the aisle wheelchair.

To understand the difficulty involved, you have to picture this scene: An aisle wheelchair takes up pretty much the whole of the aisle, with just a couple of centimetres clear on either side. To lift Nathan out of a wheelchair, seat, chair, or anything else, I have to be able to slide my arms under his body, one under the legs and one just above the hips; then – and this is the most important point – I have to be able to position the feet so I'm not leaning forward, so I can lift with my back straight and my head up. This all has to be done with me standing beside – not in front or behind – the wheelchair.

Phillip and I move around Nathan, try our hands in the right positions, shuffle our feet into the closest proximity of a lifting position that we can manage, and then stand back to review our options. They aren't very good, and both Phillip and Pretty But Stubborn now know it.

Meanwhile, outside at the departure gate, the crowd is getting restless.

‘Could you lift him from shoulders and feet?’ asks Pretty But Stubborn. The smug smile has disappeared. This is taking longer than she had thought it would and she is reconsidering her conviction that the aisle wheelchair has to be used.

I know how this is going to end before we try this new tactic, but I go along with it anyway. Phillip insists on taking the shoulders, as it’s the heavy end and he is younger, bigger and stronger than me, and I take the feet. ‘Are we ready?’ I ask. ‘One, two, three,’ and we lift.

Nathan is 55 kilos, and that’s 55 kg of dead weight; he cannot assist our lift at all. Phillip is leaning forward over the back of the wheelchair in a lifting pose that would give a biomechanist the horrors. We get Nathan out of the aisle wheelchair, Phillip is turning red with the effort, and then he and Pretty But Stubborn realise what we had known all along.

We cannot move the aisle wheelchair out of the way. It’s stuck there, between the two lifters, and under Nathan’s body, and there’s no way on God’s earth we can get it out of the way, so we cannot carry Nathan to his seat.

We carefully lower Nathan back into the aisle wheelchair. I look around for Pretty But Stubborn. I have some gloating to do, but she’s done a runner.

We take Nathan back to the entrance to the plane, I lift him out of the chair and carry him to his seat.

Negotiating the narrow aisles and edging Nathan into his seat is not easy, but I manage it. I have to, there are seven plane flights on this holiday and I’ll have to carry him to his seat on each one. Once seated, we have a five-hour flight with nothing to do but worry.

As the plane wings its way across the Pacific, I wind through all the things we had to go through to get here. We planned to go; we cancelled; we planned to go again. It took so much planning – how did we ever get this far?

Val, I should point out, is 160 centimetres of organisational dynamism. She has been planning this trip for seven months; her nephew is getting married in Costa Rica. We started out by taking Nathan to the Royal Children's Hospital in Melbourne, to hook him up to a flight simulator, to see how his lungs would respond to the low oxygen levels of an international flight. Actually, we had to do that twice, because the first time he had a cold, and when he was hooked up to the finger device that read his blood oxygen his reading was so low that the medicos refused to put him in the flight simulator. At that point, we mentally cancelled our trip, but we kept the second appointment, post Nathan's cold, and he did so well that time that we resurrected our plan.

Next in the big holiday plan we had to learn how to replace Nathan's stomach peg through which he gets all his feeds, fluids and medication. It had come out once before, and we'd had to go to the Children's Hospital in Melbourne to have it replaced. If it came out during our trip, we would have no chance of finding someone with the expertise to replace it, we'd have to do it ourselves.

And then we had to plan Nathan's diet. We have to be very careful with his diet, and we didn't want to feed him food we bought in a third world country. We decided that everything on this trip would go through his stomach peg, so we had to arrange tins of formula for peg feeds, tins of fibre booster for the formula, and feeder tubes. Finding the right formula for a kid of Nathan's size was one thing, working out how much he would need on a three-week trip was something else again.

Then there was another next, and another, and another, and another, all carefully thought through in Val's computer-like brain, with scripts for drugs and extra scripts in case the originals got lost, letters from doctors for customs authorities, solutions for bladder and bowel regulation, solutions in case of illness – which I was sure we wouldn't need – and a hundred and one other back-up plans and contingencies for taking a disabled boy on a long trip to a third world country.