

NEW WRITING

A Town Like Alice

Episode 4

A Diary by Deborah Berkeley

Alice was born in July 2006. Deborah has kindly agreed to keep this diary to report on what has happened in their family life so far and to keep us up to date with developments. Deborah, Vince, Alex and Alice are pseudonyms, but all locations are real. To see the previous installments please go to IQJ Issues No. 1, 2 and 3.

January 2009

- Hospital Appointments in last 8 weeks: medical paediatrician, dietitian, vision clinic
- Child Development Centre (CDC) appointments: developmental paediatrician, physiotherapist, SALT, Portage, family psychotherapist, occupational therapist
- Specialist teacher
- Health Professionals: 16

This year's resolution: Spend less time at CDC (unless I'm being paid!)

Clinics to come: GOSH gastro team (reflux investigation), audiology

This month's rant: New Year, Same Old Me!!!

So. Another year passes. I'm not a big fan of new years. Maybe (and I'm warning you, this is going to get self-indulgent!) it's because everyone seems to be moving on except me. I'm the only person I know who appears to be heading backwards. I wanted to lose weight in 2008, yet I gained a stone. I wanted to earn more, and I haven't. And I wanted to be more organised, in every way, but didn't do it. Luckily, my inability to dig myself out of a rut hasn't affected the rest of the family. Vincent's taken on more IT responsibility at school. Alex is reading chapter books all by himself, searching on the internet, looking for mash-up versions of his favourite hip-hop tunes on YouTube. And whilst Alice hasn't come out with any more actual words, she can now ask clearly for more milk by bringing me the empty bottle and batting her eyelashes winningly until I refill it. Even the crocuses, resting in a dark cupboard, are sending little shoots of promise into the January greyness.

In the CDC, there have been even more changes. Luckily, Alice hasn't noticed—I don't think she really takes much notice of who her therapists are. I miss them, though. Much-loved SALT has got a new job. Nearly as much-loved SALT and possibly a paediatrician are taking (separate) career breaks in the Antipodes. An OT is heading back to South Africa. Dietitian's pregnant. And various physios (all of whom seem to up sticks

pretty regularly) have dispatched themselves to 'the community', never to be seen again.

Talking of the community outside Special Needs World, previously in-a-rut friends of mine are also waking up, having great ideas, acting upon them, and getting big fat yeses. One's set aside her 20-year fear of roads and passed her driving test. One's got an MA. Another's turned suburban exile to her advantage and started a recycling company. And—best success of all—the newly cancer-free friend who perhaps deserved a break more than anybody else, has had her first book published, to growing acclaim. It's not the definitive N London-vegetarian-kick-ass-detective novel I've always wanted to write, so there's no bitter-with-a-side-order-of-twisted from me. I'm just pleased. And depressed.

Because however much I am inspired by them all, with their movings-on and their journeys into the unknown (or at least, the A10) and their radio interviews, I seem as stuck in a rut as ever. And I'm really cross about it. Because in my heart of hearts, I know I am capable of much more. But perhaps part of me likes the lack of expectation that surrounds me since Alice came along. I don't admit it though. People still say to me (in relation to the couple of pieces of journalism I write every six weeks or so), 'I'm amazed you find the time to write anything at all', but in truth, Alice is much easier to look after these days, and I've got enough time in the evenings to get stuck into a project or two.

Yet I'm no nearer getting my life together than I was this time last year—or the year before, or the one before that...goodness knows why there's such a strong drive for me to sit, slack-mouthed and lumpy in front of the television instead of Getting Creative, but if it's Alice's fault, I fail to see the connection. Perhaps I just have nothing to say. Perhaps this is what happens in Special Needs World, if you aren't careful. All those appointments, assessments, labels, tests and rulings-out diminish you, tiny piece by piece. Until you have no you left. Just a lumpy hulk in a green parka style jacket, waiting endlessly at the bus stop, for a ride back to your old life, which never seems to materialise.

Your baby might be growing up and reaching her milestones, but watch out, mum. It's your turn for the developmental delay diagnosis...

More soon...

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