

NEW WRITING

A Town Like Alice

Episode 3

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 instalments please go to IQJ No. 1 and 2.

October 2008

- Hospital Appointments in last 8 weeks: medical paediatrician, dietitian, orthoptist, GOSH (Great Ormond Street Hospital for Children) feeding team
- Child Development Centre appointments, physiotherapist, SALT, portage, family psychotherapist
- Health Professionals: 16

This month's champagne moment: Alice's first words!

This month I'm also concerned about: my own mental health.

Clinics to come: GOSH gastro team, developmental paediatrician, audiology.

After a relatively quiet August, (which was spent entirely in London, credit-crunching) Alice's therapies have resumed. At present, Portage and speech and language therapy are offering weekly appointments in alternating six to eight-week blocks: she doesn't need regular OT or physio at present, but we do have a programme of exercises to perform at home.

With the SALT, we'd been focussing on the very basics of communication: the idea of a two-way, turn-taking process. You do something, then I do something in response. It's something Alice never seemed able to 'get'. Despite everyone at home, nursery and the CDC making Makaton signs aplenty, she never copies anything but a wave hello or goodbye, and never 'asks' the adults looking after her for what she wants, by pointing, gestures or sounds. Instead, a hungry, thirsty or bored Alice simply cries until the correct item or environment is provided.

Every day, Alice would shriek with pleasure on her push-along trolley, never connecting that the magic word after 'ready, steady...' was always used before mummy or Alex took her for a fun whiz across the living room. But on 25th September, after much repetition with our patient SALT, with a succession of intriguing toys that all needed that special word to make them perform, the connection was suddenly (and irrevocably) made. 'Ready, steady...' I prompted for what seemed the thousandth time. 'Go-oh!!!!!!' she chirruped. 'Go-oh!!!!!!'

Obviously a child's first word is a huge milestone whenever it appears, but I don't remember being anything like as proud of Alex: he produced his first phrase, 'bye-bye' at exactly the same time as his friends from NCT group, and it had long been obvious that his receptive language was pretty well developed—by two, you could tell him it was park time and he'd be in the hall cupboard, grabbing a ball. Whereas Alice will just smile prettily at me and show no sign that she understands. At least now I know that she's connected words with action.

Since then, Alice's communication has improved daily. She can say 'A-ecks' (Alex) and 'Good girl' (with thumbs-up Makaton sign) and we think she's trying to sing 'Twinkle Twinkle!' No 'Drink' 'Hungry' or 'Mummy' yet, but there's plenty of time. I look forward to being one of those whingey parents in the playground, the sort who complain loudly that they can never hear themselves think, "cos little Madam never shuts up asking questions, talking, and singing loud songs.' So go, go, go Alice—I can't wait to tell you to be quiet!

Up and down: keeping it in

It's all very well telling everyone about Alice, and what's wrong or right in her life, but when I try and make things a little more personal, boy is it hard to write! Suddenly, I am afflicted by a tremendous need to discover all that Google can tell me about the state of Madonna and Guy's marriage, to do the washing-up, or to repaint the entire flat. Words about Alice trip easily enough out of my head and onto the screen, but I've already been sitting at my computer for over half an hour now, trying but failing to find the right words to talk about me.

And yet, talking about me is partly why I am here, in this journal, writing this diary. I'm not saying my reactions over the past two years have been typical, or desirable, or healthy. I wouldn't actually know, because, until very recently and at my initiation, I don't remember having any proper conversations with any of the health professionals we have seen, about how we might be coping, as individuals and as a family.

I couldn't find anything to read, either—apart from the occasional article about women I couldn't really relate to, either because they had children with completely different issues, or their lifestyles were too different from mine.

So here are four things I would love to have told myself two years and two months ago, when I was lonely and scared in special care, wondering if my vulnerable new baby would even live to grow into second-size clothes...

Beware health professionals asking how you are feeling—they don't really want to know.

Newly arrived in the special care unit and still recently post-natal, my midwife appeared for a visit. Clocking the baby, just fitted with nasal

gastric feeding tube, and me—sobbing, sleepless, terrified and guilty, guilty, guilty (I was convinced at the time that all Alice's problems were due to my age, 44) the midwife said, 'How are you coping?' To which I replied, 'Not very well. Is there someone I can talk to?' She thought for a moment and said, 'You can phone our office number if you want—we won't be there, as everyone is on holiday this weekend, but you can leave a long message on the voicemail.' The scary thing about this was that she actually thought she was being helpful.

Husbands often don't want to know, either.

Here comes the serious bit. My relationship with Vincent has definitely suffered since Alice was born. I have a lot less patience, time and energy for him and in turn, he is finding it increasingly difficult to talk to me. He has lots of love for Alice and Alex, but the romantic side of our relationship has definitely got lost along the way. We are just co-parents now: I hope this changes, but it shows no sign of doing so at present...

Did having Alice change us, or did it just exacerbate the problems we already had? I think having a child with special needs has brought out the fundamental difference in our attitude to life: I am a realist, he is in denial. When it comes to her various appointments I am organised, punctual, well researched, and well informed, so I can make an informed decision about whatever is being proposed. Vincent avoids nearly all of the therapists and hospitals, so that he can maintain his fantasy that Alice is 'a little bit delayed but will catch up soon'. I find this attitude almost impossible to bear, especially when he wimps out of GOSH appointments because he doesn't like GOSH. Nobody likes the place. It's full of sick kids!

You won't find solace in the fridge—however hard you look

In my teens, I was bulimic, and it's left me with a compulsive eating habit, which worsens under stress—it's as if, whenever I try to be healthy, the chocolate, biscuits and sweets call to me, saying, 'eat me, you'll get a lovely break from all your worries'. Eventually I give in and live on indulgencies until I get to a certain cut-off point (for example, being unable to fasten a favourite pair of jeans) and then put myself on a rigid diet to get back into them again. I keep it up until I

can bear it no more, then eat my way back out of the jeans again. It's ridiculous and I am sick of it. I have no idea where the term 'comfort food' comes from—it's more like 'torture food' in my case.

When things are good, prepare to crash.

Alice's first 18 months were full of fear and anxiety, on my part. First I needed to get her to take enough food without vomiting, then she had to recover from her various viruses and colds (all of which seemed to go to her chest, make her vomit in the middle of the night and prevent her eating). If I had time I worried about which dreadful metabolic condition she was being screened for might be The Diagnosis.

And then, in January 2008, Alice suddenly started walking, eating and generally being germ-free. Her smiles became more frequent and she began to play a little with her brother. And I think I felt, 'phew, I don't have to work so hard now', and turned my attention away for long enough for all those old insecurities to come back: 'I'm an old mum, I'm fat, useless, poor...' in the past such badly behaved voices would have been banished by a bottle or two with my girlfriends, or by throwing myself into work: but being so home-based with Alice I'd reduced my social circle and worked from home.

I'd never known self-hatred like it: I was torn between telling myself to be quiet, and agreeing with all that I said. And so I went to my GP and explained that now Alice was better, I was worse. To my surprise, he seemed to understand exactly how I felt, and I have the anti-depressants to prove it. Have they worked? Yes, in that the feelings about being useless are much diminished. But the eating side of things is far worse, and that's why I am giving them up after three months. I have to withdraw slowly, but it looks as though the next episode in this diary will not be written under the influence of drugs. Which may be a very good thing indeed—I'll let you know.

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More soon...

If you would like to make contact with Deborah please contact Interconnections.