

NEW WRITING

A Town Like Alice

A Diary by Deborah Berkeley

Alice was 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. This is the second instalment of Deborah's Diary. At the end of the first episode Alice was being transferred to the SCBU (Special Care Baby Unit) where she would stay for five weeks. Here Deborah first brings us up to date and then goes back in time to that five-week period. Deborah, Vince, Alex and Alice are pseudonyms, but all locations are real. To see the first instalment please go to IQJ Issue No. 1.

July 2008

- Appointments in last 4 weeks: 12 (ophthalmology team, audiology consultant, ENT consultant, occupational therapist x2, SALT, physiotherapist, educational psychologist, child psychotherapist, phlebotomist, GP)
- Hospitals visited: 3 (Moorfields – to get new glasses – yes, again!), Homerton, Great Ormond Street.)
- Child Development Centre appointments: 5. Health Professionals: 16

This month's big issue: Why won't she speak?

This month I'm also concerned about: Our mental health. Now that the first crises are behind us, it seems Vince, Alex and myself all need a bit of attention. More of this in a future episode.

Clinic to come: Great Ormond Street's feeding clinic.

Alice doesn't talk yet. There's a bit of babbling '*mummmum, bah, adoo*'... but nothing else.

And if I had a pound for every time someone's mentioned Einstein's alleged speech delay, or told me '*but she's only 2!*' I wouldn't be typing this in a scruffy, dusty attic. I'd be dictating it to flunkeys whilst reclining on an Eames sofa.

That's not to say she doesn't communicate. She makes eye contact and has a very expressive face. She can't point yet but she will try and reach the toy she wants, or stand at the staircase and cry, until I work out that maybe she is hungry, thirsty, bored with being indoors (quite frequent at the moment) or simply fancies a visit to the kitchen to see what the washing machine's doing.

Our SALT (speech and language therapist) has been working with Alice since she was about six weeks old – initially on feeding issues, but now with speech too. She introduced me to Makaton signing, which uses some elements of British Sign Language but is more of a communication aid for non-verbal children than a language in itself. I've been using the signs for everyday

words – *hello, good, drink, eat, more, finished, stop* (very important, that one!) – for about a year. Alice can now sign *hello* independently and appropriately, i.e. not simply by copying me, and the other day she managed to do a thumbs-up sign (Makaton for *good*) and was immensely proud of herself!

As we don't have an overall diagnosis for Alice, we don't know what's causing her speech delay. But having glue ear certainly hasn't helped. At about a year old she was diagnosed with a moderate hearing loss and her audiovestibular consultant explained that, although it's possible, albeit rare, for hearing loss to be caused by a malformation of the bones in her ear, Alice's problems were most likely caused by a build-up of sticky fluid ('glue') in her middle ear which was preventing the sound from getting through – imagine trying to hear conversation underwater. In some children the glue drains away naturally, as the Eustachian tube matures, but in others, like Alice, it hangs around until siphoned off by a surgeon, who then fits little pipes called grommets into the ear-drum to whisk away any future fluids.

Alice had her operation on 23 April. After only a couple of days, she began noticing when the television was switched on, looking scared when her beloved washing machine went into spin cycle, and turning her head to hear the phone or doorbell. Her own noise-making didn't change, though.

I wasn't expecting her to wake up and start talking, but I was disappointed that there wasn't more of a tangible improvement. Especially when, at her recent follow-up appointment at Great Ormond Street, I was told she still had a hearing loss. Luckily, her far more positive local audiology team repeated all her hearing tests and were able to report that her hearing had in fact improved greatly and her losses were now so mild, they were probably just caused by a bit of wax blocking the grommets. Next appointment is in a month – I'll keep you posted!

Back to the SCBU

Life in the SCBU felt surreal. Six stations, each occupied by a baby in a Perspex cot. Six chairs, each occupied by a zoned-out mum.

And several nurses, quite a few of whom could best be described as 'characters' – the stressed Scottish one; the calm Nigerian one; the evangelical Christian from India (who gave me a lecture on accepting Christ and assured me Alice's health would improve if I did) the nutter, the knitter and all character types in between. And all punctuated by the bleeps of the oxygen monitors, the ringing of telephones, and on one memorable occasion, a woman giving birth on the floor of the labour ward next door!

But perhaps the most unexpected sound was the one you *didn't* hear. The post-natal ward had been filled with the lusty cries of healthy newborn babies. And here, for the most part, they simply slept. One or two, nearing the end of their 'sentence' would cry for milk. But by and large, these little inmates just got on with the business of doing their time. Concentrating on growing healthier, bigger, stronger. I'd spend all day gazing at Alice and willing her milk to stay down, to make her well. And before I knew it, it would be time to pump yet more milk and measure it carefully into her nasal-gastric tube.

More soon...

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