

A Town Like Alice

A diary by Deborah Berkeley

Alice was born 19 months ago. Deborah has kindly agreed to keep this diary to report on what has happened in their family life so far and, in future issues of the IQJ, to keep us up to date with developments. Deborah, Vince, Alex and Alice are pseudonyms, but all locations are real.

against her ear, necessitating a further schlep to Moorfields?

2. Why did it take three weeks of calls/emails to elicit one overdue appointment with the community paediatrician?

Easter 2008

- Appointments this month: 7 (Portage, dietitian x 2, ophthalmology team, optometrist, audiology, ENT consultant)
- Telephone consultations: 1 (dietitian)
- Hospitals visited: 3 (Moorfields—to get new glasses); Homerton (dietitian/orthoptist); Great Ormond Street (ENT and audiology)
- Child Development Centre appointments: 1 (audiology)
- Health Professionals: 15

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

This month I'm also concerned about: visible disability (glasses alone = OK, but glasses + hearing aid = special needs...)

Gripe of the month:

1. Why, when I told the optometrist that Alice wore a bone conductor hearing aid (being repaired at the time), did we end up with glasses that squash the receiver

Our history

My name is Deborah and I am 46. In another life, I was a journalist and I still write the occasional feature. This month I'm writing about how to look good in family photographs. In fact I'm supposed to be doing it right now, but the diary's more tempting.

I live in a little flat in N London with Vincent, 46, a primary school teacher, and our children Alex, six, and Alice, 19 months. Alex hates football, loves chocolate and is obsessed with Dr Who. In short, a normal little boy.

There are also some 'normal' things about Alice. She's super-cute, smiles a lot and, being new to walking, staggers about like a drunken uncle at a low-rent wedding. If there are drawers, she will try and open them. She opens cupboards and tries to climb stairs unaided even though if left to her own devices she would get to about the 4th step and flop backwards. She also launches herself off stairs with no fear whatsoever. A future base jumper! Obviously we are delighted she can move around so well. But it doesn't make visiting cafes or friends' houses any easier!

But the reason I'm writing this diary is that Alice has **global developmental delay** (GDD) which means she isn't hitting her developmental milestones on time. So although she is 19 months old, she's behaving more like a 12-month-old.

It's highly likely we'll never get a diagnosis at all—up to 50% of babies Alice's geneticist sees never do. But even children with a diagnosis vary tremendously. With no known cap for her achievements, perhaps, with enough encouragement, Alice might catch up her peers one day. On the other hand, though, if we knew she had something life-limiting, it might be good to be prepared. Maybe we'd sell everything we have and go somewhere more beautiful than Hackney. Maybe we'd stay put to keep our friends close by, and keep things normal-ish for her brother Alex. Sadly, it is something I have thought about. A lot.

These are the issues I live with every moment of every day. Positive one moment, depressed the next. She can't/won't eat. She's struggling with the basics of communication. She's walked her first step! She can't use a spoon. She's had half a slice of pear. She's kept her hearing aid on for an hour without trying to eat it.

What else is wrong with Alice?

Speech hasn't happened yet; she doesn't point to things she wants. She **can't yet feed herself** or manage a sippy cup. In the past, she's eaten solids, but since November, she has gradually lost interest and is now dependent on high-calorie formula milk which we get on prescription. She does communicate, however—there are smiles aplenty and she is beginning to play turn-taking games.

Alice wears glasses with a plus 3 prescription, to cope with her **long-sightedness and squint**; and has a bone conductor hearing aid for **moderate hearing loss** (which might only be temporary—depends what happens when the 'glue' in her middle ear is drained).

She also has **hypotonia** (which means she's on the floppy side) and **hyperflexibility** (which means her joints bend beyond the normal range of movement).

Team Alice (I hate Americanisms, but what else could I say? Maybe—if she adds any more people—A Town Like Alice)

For every different issue, Alice has a collection of health professionals. In overall charge of her development, we have a **community paediatrician**, who sees us every six months or so at the child development centre. Unfortunately, there have been three of them so far, so for our April appointment (which should have been a January appointment) I've requested that we see the consultant who saw Alice at her first appointment, just to get some continuity.

We also have a **consultant general paediatrician** at Homerton Hospital who looks after the medical side of things. Eventually we should be able to manage without him, but Alice has had some ongoing weight gain problems and isn't eating solids at the moment, in addition to lots of upper respiratory tract infections over the winter, so we need to keep him for now. I think it's hard for him not to be able to provide a diagnosis. He says when he can't say what the diagnosis is, he likes to at least help parents out by taking on a chasing-up role, sorting appointments out, etc. But as I'm my own **keyworker**, he can't even do that!

Alice also has a **neurologist** at Hammersmith Hospital, who calls her in for MRI scanning now and then (there are some things on her brain they can't explain but unfortunately none so far point to a diagnosis).

There's an **orthopaedics surgeon**, at Royal London, to look at her wonky hips (they aren't wonky enough for any treatment to be required, thank goodness).

Then there's also an **audiovestibular consultant** who looks after her ear problems and diagnosed her deafness; a **Great Ormond Street ENT surgeon**, to perform her glue ear operation; an **eye specialist from Moorfields**; and a consultant from the Great Ormond Street **genetics** team.

And on a fairly regular basis, we also see Alice's **dietitian**, a **physio**, an **occupational therapist**, a **speech and language therapist**, and a **Portage** playworker. The latter group, together with the eye team and the audiology clinic, have just all moved to a brand new child development centre. That should make our lives a bit easier, in that it's an easy walk from home instead of a long bus ride. We shall have to see!

Back to the beginning

Alice was diagnosed with ventriculomegaly (excess fluid in the brain) when I was 22 weeks pregnant. As an older mother, I immediately blamed my advanced age. But my fetal medicine consultant at Homerton Hospital was quick to reassure me that he saw this problem as frequently in mothers under 30. Some babies with ventriculomegaly have no problems but in other cases, the brain fails to develop, causing profound disability or even fetal death.

At 27wks pregnant I underwent fetal MRI scanning and luckily, Alice's brain appeared to be structurally intact. The brusque consultant at the Harris Birthright Centre was quick to inform me, however, that babies like Alice were often—but not always—so seriously delayed in their development that termination was an appropriate consideration. But bearing in mind he was unable to predict (a) whether Alice was likely to be affected at all; and (b) the extent of her disability, I declined. Besides, I'd seen Alice on screen and she was part of me, part of my family. At one stage during one of her repeated ultrasound scans, an old-style cardiac specialist, students trailing in his wake, called Alice 'a naughty baby' for refusing to move into the right position to be scanned. I felt proud—here was my tiny baby, not yet born but already asserting herself! Once duly probed, Alice's heart was pronounced 'normal' and the great man swept out, students too.

And what kind of counselling was offered to a terrified, heavily pregnant mother who'd just been told her baby might (or might not) be severely brain damaged? Absolutely none. Technically, of course, I could have spoken to 'my' midwife, if I'd had one. But like most women attending hospital antenatal appointments in London, I saw a different staff member each time.

Alex knew there was a baby on the way and claimed to be excited about being a brother, but, aged four-and-three-quarters, and newly arrived at school, he was far more interested in who he was going to sit next to at lunch-time and whether there would be noisy hand-dryers (a pet hate) in the boys' toilets.

As the pregnancy progressed my anxiety grew deeper. My 32 week-scan revealed a baby growing as it should, albeit with exactly the

same amount of fluid as before. I pressed the fetal medicine consultant on what to expect. 'Your baby might have to go into SCBU when it's born,' he explained, 'because there may be breathing difficulties or feeding problems. We won't know until it's born, but don't worry, someone from SCBU will attend the birth.'

Touring SCBU at 35wks pregnant, a friendly nurse showed me the incubators, each with a tiny baby inside. 'You'll still be able to hold and feed your baby,' she explained, 'and you'll soon learn what all the monitors mean and how to manage the oxygen...'

I was shocked and burst into hormonal sobs. 'Oxygen? Nobody said anything about that!' The nurse re-read my notes. 'Oh I'm so sorry, she said, 'I thought your baby had heart problems! Come and see the transitional care room. That's where the term babies without breathing problems usually go.'

I was shown into a bizarrely over-decorated living-room with curtained cubicles, sofas, and rocking chairs. On every possible surface there were stripes, swirls, mosaics, and friezes in a riot of peeling primary colours. The room was noisy on the ears, too, with oxygen monitors constantly bleeping as the babies moved around and set off alarms, a clunking breast-pump, and the world's squeakiest vacuum cleaner attacking the floor.

'The *Changing Rooms* TV programme made the ward over a few years back,' explained the nurse, proudly. 'It's very, er—bright,' I said, trying to be tactful and wondering how on earth I'd manage to stay overnight, let alone a week, without going insane. Little did I know that this hideous room would be my home for the best part of five weeks...

More soon...

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Editorial note

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