

NEW WRITING

Our first two years with Bertie

By Mary

Summary

In this essay Mary reflects on the first two years with her baby Bertie. She describes unhelpful attitudes and practices she encountered in some professionals and contrasts her experiences in the NHS with her experiences in a hospice. The names are not real.

Bertie had to be resuscitated at birth. His cord was occluded during an unsuccessful ventouse and he was then delivered by emergency caesarean section. He was grey having been asphyxiated by the failed ventouse. After 20 minutes of resuscitation, his heart started to beat again. He was intubated for 6 hours and then he was able to breathe for himself. What was supposed to be the happiest day of my life turned into the worst day of my life. During the resuscitation, only my husband talked to me about what was happening. None of the many professionals in theatre talked to us about what was happening although many of them were occupied looking after Bertie and me. All I could do was lie there and pray, whilst being stitched up. Before he was taken off to the Special Care Baby Unit, SCBU, Bertie was wheeled over to us. He was still grey, the same colour as the consultant's hair. In days gone by, I guess that both of us would not have survived.

That was the start of our new life with a special needs child. Our lives are not our own. They are pored over by well-meaning strangers with varying roles on an ad-hoc basis. These strangers

are experts in their own fields after years of training and research. They come and go with job changes. Suddenly we were to become experts in all Bertie's conditions, over a much shorter period of time.

Bertie was in SCBU for 12 weeks. Initially, he had no swallow or cough reflex. He was fed by a tube via his nose. At first, we were told that he would struggle to survive 2 hours, then 2 days, then 2 weeks, then 2 months and then 2 years. Following the birth, we worked out that he would have cerebral palsy but we weren't officially given this diagnosis for many months. We were also told that he might suffer from fits, which thankfully did not happen. We also discovered that the registrar and midwife had been offered counselling. We were offered none.

We asked if we could speak to other parents who had been through a similar experience. The first couple we met had a little boy who had a difficult birth and died when he was about 4 months old. We were also informed by the consultant that Bertie was unlikely to survive for more than a few months. A few days later Bertie learned to cough so he could clear and protect his airways. The nurses on SCBU continued to use suction and didn't let him clear himself so I had to suggest that he cleared himself initially and if he struggled, then suction would be appropriate.

Then it was suggested that we should meet a second couple whose daughter was then 5 years old. It dawned on us that this was the consultant's way of suggesting that Bertie might

live longer than initially expected although it was always stressed that the first 2 years would be difficult – she wasn't kidding! I imagine it is very difficult to make a prognosis as it can change from day to day. However, parents need honest and realistic conversations about this, probably more frequently than case loads permit.

I have very little recollection of both these meetings because I don't think that I wanted to hear the messages that we were being given. One of the best things that the consultant did was to refer us to our local children's hospice. From moment that I stepped through the front door of the hospice, when Bertie was still in SCBU, I had a feeling of support and love which has continued to this day. Hospice staff training must be different to NHS staff training. SCBU was a busy place with lots of people coming and going whereas the hospice felt like a haven. The atmosphere was calm, friendly and supportive. On my first visit (and on every visit since), a cup of tea was offered. There is always time to talk on a comfortable sofa about what is happening and how you feel about it. It was like being with family, but a family that understood this new and challenging world into which I had been thrown.

Bertie was discharged from SCBU (with heaps of equipment) at 12 weeks. He had already had three visits home before discharge, one day visit (with a lovely nurse, Margaret, with whom we are still good friends) and two overnight visits. It was very difficult to adjust – I felt very lonely and scared of what we had to do. I recall taking Bertie back into his first clinic appointment at the hospital. I was looking forward to seeing some familiar faces at the clinic. I came out feeling quite low because I realised that, for the health care professionals, this was a job that they could leave behind when they went home. For me, this was 24/7 for life. Within a fortnight of being discharged, Bertie got the first of many chest infections which meant he was hospitalised. This happened about 10 times in his first 2 years.

Looking back

Before Bertie was born, I had a successful career as a senior finance professional. I had been working in a firm of accountants for 14 years (including as a partner in the firm the previous 4

years). I suspect that I was quite a tough person. Then I was sucked into a tornado of emotions about my feelings for Bertie and his future. This was at the same time as having to keep family and friends updated on his condition and prognosis. I kept working until last year (2007) when I decided to take a sabbatical to understand Bertie's world. I think that I am now a gentler person, focussing on what really matters in life.

I think I have a reasonable level of intelligence. However, some health care professionals have patronised me and Bertie by their lack of tact or empathy. They can also imply that I am panicking unnecessarily or leave me feeling "processed". A friend recently said that when she took her "normal" child to the GP in her "mummy" clothes, the attitude was quite different in comparison to when she took her child to the GP in her work suit. Then she was treated as an adult. Bertie's first community paediatrician was very kind. He advised that, as parents, we knew best and we had to ensure that Bertie got what he needed even if it meant asking twice or more.

One of the most difficult things about the early years with Bertie was constantly wondering if each choking cough during the night would mean hospitalisation – which could mean that we had to steel ourselves for his life coming to an end. When Bertie was 20 months old he got a very nasty virus which meant that he was admitted to the Paediatric Intensive Treatment Unit, PITU. He had to be intubated because his airways were so swollen. There was a real difficulty in inserting the tube and we nearly lost him. He was intubated for 10 days. However, Bertie has continued to fight to survive and thrive. We have done all that we can to support him.

Another difficult thing has been that the negative messages from the health care professionals made it difficult to bond with Bertie. I felt caught between a rock and hard place. I felt that getting close to him when he might not have long to live would mean that losing him would hurt much more. I wonder if men tend to stand back from a sickly child for that reason. Ultimately, my instinct was to do all that I could for him, taking one day at a time. It is fair to say that in the NHS some professionals were not as helpful or as understanding as they

could have been – as the following examples show.

I stayed in hospital for the first 10 days after the birth. When I went home I had to arrange lifts to SCBU to visit Bertie from our home 10 miles away as I couldn't drive for 6 weeks after the caesarean. I had decided that one thing I could do to help Bertie was to express my milk (using a machine at home) in the hope that the nutrients would help him to thrive. No-one told me that there was a room and a machine for expressing milk on SCBU, so my visits had to be limited to 2 hours to allow time to get to and from home to express milk. This was physically tiring in addition to the emotional trauma that we were experiencing. At about 4 weeks, someone realised this and told me that there were expressing facilities on SCBU. (However, my milk started to dry up after the meeting with the first family.)

Bertie had a gastrostomy operation when he was 6 months old. The theatre recovery nurse had showed me how to administer the patient controlled analgesia, the PCA. Back on the ward, the nurse on the afternoon shift was content for me to continue to administer the PCA through the afternoon. My opinions about professionals will acknowledge that they are limited in time and resource which is outside their control. However the night nurse after the operation was really unpleasant and rude. In fact, I would say she was the only nasty health care professional that I have encountered over the years to date. She waited until I was on my own when my partner had left to go home. I was staying on the ward overnight after what had been a long, emotional and stressful day. I recall that she said *"You shouldn't be giving the PCA. I am sure that you don't want to harm your child and this is a task for me as the nurse"*. Fortunately, I was able to take Bertie to the hospice to recuperate from his operation on the following day, which was fantastic for both of us.

It wasn't until he had this third winter (2002/2003) without a hospital visit that I felt we could perhaps enjoy life with Bertie and that we all deserved to have fun in our life. Bertie is now 8. We took him to Disney in Florida last June! He has just started to sign. He is trying to walk and loves yoghurt although he is still gastrostomy fed. For all his health problems and

developmental delay, he is very well natured and sociable.

So my messages to health care professionals are:

- Please remember that parents know their children best
- Encourage and support our development with your technical knowledge and experience
- Put yourselves in our shoes – we don't want pity and platitudes and inappropriate opinion
- Take the trouble to read the file before you meet us
- Please put the child at the heart of what you do and recognise the key role of the parent

We need to work together, not against each other, for best use of everyone's resources and energy.

Editor's note

If you would like to make contact with Bertie's mother please contact Interconnections.

Do you have theories, analyses, surveys, research, etc. about how the hospice experience differs from the NHS experience? Please contact Interconnections.

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