

## The parent's view

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Writing this article has been demanding. I am very aware that many people find it difficult to hear about and accept strong emotions. What I have written may evoke strong feelings in the reader. My aim is to present the parents perspective which is, by definition, subjective and emotional.

David and his twin sister Miriam, were born in London, at 27–28 weeks, in February 1983. Although David had to be ventilated for six days, he and his sister made good progress. After 10 weeks in the neonatal unit we brought them both home to join their 2½-year-old sister, Sarah.

We spent a happy summer with our two new children who appeared to be thriving. In October, when he was eight months old, David developed a persistent cough which made feeding difficult. After several visits to the locum GP, who prescribed Actifed, I eventually saw my own doctor who knew David's history and gently suggested that he should be admitted to hospital for observation.

In hospital, David was put in a croupette. During the next 36 hours he went rapidly downhill. He ate nothing, drank very little and thrashed around continuously, unable to rest.

### Getting information

Getting information was difficult. The sister was in charge of two wards and rarely available. Those directly involved with David's care were student nurses who had nothing to tell me.

I became desperately concerned as David seemed to be too exhausted to maintain the effort of breathing. Unlike the neonatal unit, there were no doctors or experienced nurses available to help, reassure me or answer my questions. I had not seen a doctor since David's admission as my visits had not co-incided with ward rounds. I was frightened to leave my child unattended, but decided I **HAD** to find a doctor. I left a student nurse at David's bedside and told her not to move till I returned. I couldn't find a doctor on the ward or on the neonatal unit—so I rang my GP who said he would come. I ran to the doctors' offices and begged someone to come and see David. Finally someone arrived.

I tell this not to apportion blame, but to demonstrate the parents' perspective. Is it reasonable to expect a parent to wait silently and unsupported by the side of their child who is struggling for breath? If I had done so, my son might have died.

### Being transferred

It was quickly decided that David should be transferred to University College Hospital I have since learned that this was problematic. It was a Friday and apparently, some district hospitals, believing that teaching hospitals have better weekend staffing levels, try to reduce their weekend workload by transferring borderline manageable cases. As a result, teaching hospitals are sometimes wary of accepting transfers on a Friday.

### Trusting my instincts

During the ambulance journey, David's eyes were rolling up into his head and he was foaming at the mouth. I shall never forget how wonderful it was to be met at UCH by staff who took me seriously. I had spent some hours knowing that David was heading down a dangerous path, but had no professional medical knowledge myself nor any backup from the staff. We are not brought up to trust our instincts—but I'm glad that I did. The way I was received at UCH was confirmation that my instincts were correct.

Since then, many doctors have gravely told me "you were quite right to trust your instincts" . . . "always listen to the mother" . . . "they always know" . . . In the light of experience, however, I had found it necessary to bellow at the top of my voice before I could even find anyone who would listen with any attention.

### Intubation

On the ward, I was shown how to give David oxygen which helped me because at last something was being done. Within minutes he was taken to theatre and intubated. This proved difficult. His airway was so swollen that it was impossible to intubate through his nose and the tube had to be passed directly through his mouth.

It's odd the comments that stick in one's mind—some time later a member of staff said to me that, in the theatre, David 'had knocked on the door' two or three times. I nodded politely but then realised I hadn't the faintest idea what was meant. 'What door?' I asked—'Oh the door to heaven' came the reply. To this day, those words make my stomach turn over.

David had acquired subglottic stenosis as a result of his six days ventilation at birth. The next few weeks were pretty harrowing. David was intubated, partially ventilated and heavily sedated. Our spirits soared and sank in response to his progress and setbacks.

### Cricoid split

A laryngoscopy revealed continued swelling and it was clear that we needed to consider further treatment. A cricoid split was the first possibility. We were told that this operation, which was explained to us in detail, had a 50 per cent success rate. We readily consented. We did not know till later that only six cricoid splits had been performed so far at UCH! Unfortunately the operation did not solve David's problems and we waited anxiously for the next proposal.

### Tracheostomy

Since the next option was a tracheostomy, we agreed to wait and see if the swelling would subside spontaneously.

A week later, a routine laryngoscopy revealed an increase in the swelling and David had a tracheostomy. By then, we had had time to adjust to the idea of a 'trachy'. The staff clearly expected us to be upset. Our son's throat had been cut and we had to cope with seeing a hole in his neck with a pipe stuck into it. In fact the sight of our child, released from the tubes of the ventilator and the knowledge that he would no longer have to have his arms restrained, helped us to accept the tracheostomy.

### Transfer

Transition from intensive care to the general ward seems to be difficult for most families and we were no exception. We had got used to the bright lights and sounds of what was for us the second stay in a neonatal unit within eight months. From the parents' perspective, there is a special atmosphere—controlled calm, efficient and confidence-inspiring.

Transferring to the childrens' ward was quite horrific at first. All the noise! Children crying, playing, eating, being sick. Organized chaos rather than calm control! It was four days to Christmas, the doctors wore funny hats and tinsel around their stethoscopes—wonderful for the long-term patients but a shock to those newly transferred from the neonatal unit. It takes time to build trust between people, and for the first few days we felt very cut off from our dear friends in the neonatal unit.

### Learning to look after a tracheostomy

As soon as we arrived on the children's ward we were encouraged in a very gentle way to become involved in 'trachy' care. My husband Clive and I experienced a range of emotions which I have since discovered from other parents are common.

- Fear I'll do it wrong; I'll never learn to do it properly; I might kill him.
- Disgust I don't want to look at him; the wound makes me feel sick; I certainly don't want to see what's going to come up through the catheter.
- Grief Why did this happen to me? What did I do to deserve it?

Anger You've done this to my baby and now you want me to help? How dare you put yet another load on me? I've got enough to cope with already—I can't take any more.

I needed a couple of weeks to observe the staff and to build up my inner reserves of confidence before I dared to try sucking out David myself.

Having been brave enough to take this step, I gained confidence and soon felt at ease with the equipment. Looking back, it would have been easier if the staff had admitted to us then rather than later, that everyone is frightened when they first learn to change a tracheostomy tube.

Minimizing the fear and anxiety certainly increased my feelings of inadequacy. It is important not to underestimate how it feels to be responsible (even under very controlled conditions) for removing your child's only way of breathing and to register, however, briefly, his/her colour change and desperate struggle for breath. The emotional turmoil is awful.

Despite accomplishing the two supervised tube changes which allowed us to consider taking David home, both I and my husband Clive always hated doing it. Once David was home, Clive changed the tube, assisted by our helper. I found it hard to bear and would lurk in another part of the house till it was finished. I have since discovered that other mothers have reacted in the same way.

Although he knew it was irrational, Clive was concerned each time about getting the tube into the right place. Could it somehow end up between the skin of David's neck and the airway? Having got the tube out—would he be able to master the fear and nausea brought on by the knowledge that he had to gently force a small plastic tube into what was to us an open wound in our son's neck? It would have helped him to have had more understanding of the anatomical and physiological aspects of tracheostomy and tube changing.

### Speech therapy

Another aspect of care which had to be confronted was speech therapy. To me, the speech therapist was an unwelcome reminder of the long-term implications of David's trachy. Here was someone trying to talk to me about sign language, underlining and focussing my attention on the fact that David could no longer make any sounds. I felt terribly angry when I first met her—I wanted to hit her. I hated her and for at least a month did everything I could to avoid her. She symbolised all my fears. In reality, of course, she was wonderful.

### Being in hospital with a sick child

Parents react to being in hospital with a sick child in many different ways. I felt I had to be 'on best behaviour'. I was only too aware that I was being (very kindly) observed by the staff. Sometimes, against my better judgement, I was tempted to fall in with the staff's suggestions in order not to be seen as a 'difficult parent'. For instance I was frightened that if I showed my unwillingness to learn to 'suck out' I might be labelled as an unfit parent. I found it difficult to voice personal, and

possibly irrational fears and worries or to cry in case they thought I was unstable and unable to cope. I wanted the staff to concentrate all their care and attention on David.

I was able to cope by having my own support outside the hospital. I would not have been able to work so closely and well with the staff or to deal with my own feelings, without the safety valve of regular supportive listening from my National Childbirth Trust teacher.

### **Coming home**

We had very little difficulty in acquiring the equipment we needed to care for David at home. Sadly this is not everyone's experience. Some have a hard struggle to prise money and equipment from their local authority.

What we did lack was having anyone at home to show us how to assemble, clean and maintain the equipment. Since David's illness, UCH has appointed a tracheostomy sister to help parents and liaise between family and hospital.

We decided early on that if David was to come home, Clive and I needed someone else able to take care of a tracheostomy besides ourselves. Our mother's help learned trachy care techniques along with us. I have since met parents who have enlisted the help of grandparents, friends or relations—anyone they could trust. All agree that parents need an additional person at home who is able to use the suction equipment.

The most difficult part of bringing David home was facing up to the enormous and terrifying responsibility of having our child relying solely on us and on our newly learned trachy care techniques. We were encouraged by the hospital staff to build up our confidence gradually. At first, the slightest cough or splutter would throw us into panic and after the first night we felt utterly defeated. How would we ever sleep? Our biggest comfort was the knowledge that we could phone the hospital at any time and had the assurance that David could be admitted whenever we felt unable to cope.

In fact David had repeated chest infections and was in and out of hospital every week or so at first. These breaks gave us a few days respite from the burden of care without our having to say 'take him away—we can't cope'. His infections ceased after we stopped giving him milk or yoghurt. For some reason that could not be discovered, milk was getting into his lungs (this was confirmed by the raspberry yoghurt being coughed up via his tube every time he was given it!).

When David first had his tracheostomy we were told that the aim was to 'sort him out' by the time he came to school age. During the time at home we came to accept this. However a few months later, after a laryngoscopy, we were told that his airway had grown enough for David to be decannulated, possibly within a week or so. After so many ups and downs we had become punch-drunk and could hardly take in the news. In fact, things were not as straight forward as everyone hoped.

### **Alder Hey Tube**

The dreadful silver tube was produced. It was awful. David's stoma became very sore and he got increasingly distressed with everyone's preoccupation over blocking the tube. Although we did make some progress, it was

impossible to block the tube when David was sleeping. He would wake, coughing, spluttering and in distress. After three weeks in hospital, Clive and I decided to take David home for a while. He was now 16 months old. We felt there was a danger of treating him as a 'trachy tube on legs', rather than a sensitive, feeling child. He needed to be at home, to lead as normal a life as possible with his loving family around him. This seemed to us much more important than any more struggles with the tube. By now we were quite confident about trachy care and it was a triumph to be able to say 'let's agree to live with the tube a bit longer and let David just be'. The staff welcomed our suggestion though it felt odd that it had come from us and not from them.

### **Blocking off**

We did nothing about blocking the tube for the next month. We had reverted to a plastic (Shiley) tube and had no wish to try the silver tube again. UCH Medical Physics Department made us a rubber blocker and during July we began to block David's tube again. This time things went far more smoothly and we quickly progressed to blocking the tube all day and finally when he was sleeping. We always took the blocker out when we went to bed so as to minimize any risk to David.

### **Decannulation**

In August 1984, David was decannulated. It was a complete anti-climax! Out came the tube, David continued to breathe and that was that. I found it difficult to feel anything other than a kind of dull relief. I just could not believe that there was not another major problem ahead. There was not—David is now a happy outgoing four-year-old who has just started school.

### **Grommets**

David has had regular follow-ups at UCH with both the ENT department and speech therapy. His speech development was delayed. Glue ear was diagnosed and grommets suggested. We were not enthusiastic about the prospect of another operation, however small. I wanted to stall but found it very helpful to be shown evidence on the graph of David's impaired hearing ability. That I could understand. No if's and but's, here was the proof. The grommets certainly made a difference to his hearing and his speech, which are now completely normal for his age.

### **Feelings**

One of the things I have learned a great deal about is how different grief, fear and anxiety are in real life compared to the way they are portrayed in the media. Most couples would like to see themselves comforting each other, enclosing each other in warm, safe hugs and murmuring words of comfort and cheer.

In many cases the reverse is true! People in distress seem to turn in on themselves. It is very painful to see the person you love most 'hurting'. Very often one partner buries his/her grief in the belief that this will help the more obviously distraught, emotional partner. How-

ever, the more overtly grief-stricken partner can see this as 'not caring' and may become angry and resentful—and so the rows begin.

### **Peer group support for parents**

Since David's illness I have been involved in supporting other parents who have premature and sick children. It is often easier to express these feelings to someone 'unofficial'. It can also be a great relief to the staff to know that someone is coming in just to sit with and listen to a distressed parent. It helps immeasurably to know that one is not alone—that others have experienced the same emotional turmoil and that it is common for couples to have dreadful rows when both of them are desperately worried about their sick child.

Of course this assumes that there is a partner to share the worry. All too often we are supporting a single mother. Things are even more difficult for her, often a lot of anger and resentment is directed towards the staff and the parent supporter.

### **Balancing conflicting needs**

Being a parent is a wearing business at the best of times. Trying to provide security and be a supportive, loving parent for healthy siblings whilst worrying about a very sick child is virtually impossible. Is it more important to collect the other children from their first days at playschool, or to be with the sick child in hospital? Do you try to have normal weekends at home or take the whole family to hospital for a visit? Fit toddlers in a

neonatal unit or a children's ward are not that easy to occupy, especially when all you want to do is cuddle the sick child.

### **Looking back**

Clive and I have been struck by how clearly our experiences come back to us even after four years. As we talked it through in preparation for writing this article we both remembered how disturbing it was to find out quite early on that we often seemed to have a clearer understanding than the hospital staff had of David's needs. As predicted by the staff, we soon found that we became better at sucking David out than anyone else. We were quicker at spotting changes in his general health and we were extremely effective in controlling and clearing soreness and infections around the stoma. We must add that this is how it should be—we are his parents!

I could not end this article without thanking Clive for his endless support and strength. Together we got David through all this. It is worth emphasizing that we felt very lucky to have each other—especially having seen so many single parents coping alone.

Both of us particularly appreciate the way David's ENT surgeon explained everything to us and valued our participation in all the decisions that were taken about David's care.

Thanks and gratitude seem tiny and inadequate words to convey the depths of our feelings towards all those who contributed to saving David's life—but they are the only words we have. We can never forget or say it enough. Thank you.