Tracheostomy—a parent's view

When we were first told that Michelle was going to have a tracheostomy performed I cried in the car on the way home from the hospital. As a staff nurse, I remembered the stigma that a tracheostomy held and how we used to dislike nursing one. How we were going to cope with a young baby with spina bifida and a tracheostomy I could not imagine. All my husband and I did know was that we loved our daughter very much.

At first when she came home, we were very apprehensive that the tracheostomy tube would block with secretions, as they had blocked twice before when she was in hospital. For the first few days and nights I hung wet towels around her cot and kettles steamed constantly (the house began to look like a combination of a Chinese laundry and a Turkish sauna!).

Within a couple of days, I realised that these drastic measures were not necessary as the atmosphere at home was more humid than in hospital. Only when the weather was very dry and Michelle's secretions became very thick was it necessary to humidify the air slightly.

Michelle was a very difficult feeder, despite enlarging the holes of the teat, and winding frequently she would often cough and bring up the whole feed. At one stage she was so bad it was necessary to feed her with a bowl in front of me to catch the vomit when she coughed. (It helped that whenever possible my husband would feed Michelle for me; this helped us to relieve a lot of the tension.) Michelle was also very slow starting her solid diet. She seemed to show difficulty in the actual swallowing mechanism and would often 'gag'. But at 1 year she was taking her solids well and at long last was keeping her feeds down when she coughed.

When she began to use a cup for drinking we had to take great care that her 'dribbles' did not trickle down into her colostomy, making her cough. When she began feeding herself it became a fight to get to her tracheostomy without grabbing the suction catheter and getting food all over it. With practice one became the 'fastest aspirator in the west'.

When Michelle first came home, she required suction a lot and was a full time occupation. (As we only aspirated the top of the tracheostomy tube and did not enter her lungs we used a larger suction catheter (8 gauge instead of 6) with a low pressure of 200 mmHg we were able to aspirate mucous and keep the tracheostomy tube hole patent). In hospital tracheostomy aspiration is a sterile technique in which gloves are worn and the catheter discarded after use. At home it became a clean technique only but it did not seem to matter.

Michelle was with us every minute of the day; she would sleep downstairs with us until it was time to go to bed and would be carried to her cot by our bed when we retired for the night.

The first few nights Michelle was at home we hardly slept but very quickly learned to adapt to sleeping lighter than usual so that we could hear if Michelle required suction. While asleep, she did not require suction as her respirations were lighter, but waking she would make a little 'rattling' noise from her tracheostomy, which meant she needed suction.

If you pretended to be asleep she found out that playing with the beads on her cot attracted our attention. Michelle accepted her tracheostomy as being part of herself and would make attempts to aspirate herself, frequently asking for suction if she felt she needed it. Michelle would often explore her tracheostomy with her fingers; although it made her anxious at times, we never discouraged her as we felt it was perfectly natural for her to be curious.

The suction machine became a very important part of our lives, and visiting became a massive task, with the transport of catheters and 'baby things'.

The suction machine was usually cleaned out once a week when Michelle was asleep. When the tracheostomy eventually closed it was only when I gave the machine back to the local authority that I felt that Michelle would no longer need to have a tracheostomy (the feeling is hard to explain). We were provided with a portable suction machine as well as an electric one. This was a godsend as it meant we were able to go out with Michelle and we were no longer prisoners in our own home. Michelle loved going around the shops, especially the supermarket.

At first it was a little embarrassing as people were naturally curious about what we were doing when we went to aspirate her. From the very start we forced ourselves not to retreat into a dark corner as if we were doing something terrible. With time we learnt to come to terms with people's curiosity and found people could be very kind, though it took courage and determination to have a meal in a crowded restaurant. Children surprisingly accepted Michelle's tracheostomy more easily than adults.
When 8 months, we went on holiday to Cornwall in a caravan for a week, with just the portable suction machine. It was hard work pedalling the suction machine, but having a holiday was tremendous and we all enjoyed the break.

When we went away on holiday, strangers would remark on what a good baby we had as they had never heard her cry at all during the night. I worried that she would become frustrated not being able to tell us what she wanted or needed. She was further hindered by being a spina bifida child and therefore less mobile. Michelle became very clever, however, at using body and facial language to relay her needs—for example, pointing with her finger, rubbing her eyes to say she was tired, or moving the back of her hand over the tube, meaning she wanted suction. This is where Michelle first gained from being at home as we learnt to understand her language and interpret her needs.

Bathtime was a joy for Michelle, and the water held no fear for her. We used to lie her on her back in the water (keeping her tracheostomy above water level!). Any water that trickled down or was splashed down into her tube she was able to expectorate easily, before it went far into her lungs.

We soon got into the routine with the everyday care of the tracheostomy. Around the tube the skin would be cleaned twice a day with cooled boiled water and cotton wool. I never used sodium bicarbonate solution as I found it too irritating for Michelle's skin. For a barrier cream we found a combination of Drapolene and Sudocrem kept the skin in good condition. As Michelle grew older she would help in the care of her tracheostomy, by helping to rub the cream in. In hot weather, when Michelle used to perspire more, she did sometimes get a rash where the tapes were. We found by rubbing a small amount of Timodine into the affected areas, twice a day, then dusting over with a thick layer of talcum powder to set the cream the rash would disappear within a couple of days.

Michelle's tapes would be changed about once every three days depending on how dirty they were, and from an early age, before changing her tapes, we would always tell her what we were going to do and make a game of it. When we first began to change her tapes we found it very frightening and Michelle would sense our apprehension and would cry and become anxious. We overcame this by using an unorthodox method of tying the new tapes on while the old tapes were still in situ. The correct tension was obtained when the index finger on the left hand could just be placed underneath the tapes while the head was flexed backwards. The old tapes were then cut off. Despite being told by countless people that Michelle's little hole would not seal itself when her tracheostomy tube was removed, it was only when we saw it for ourselves we were truly at ease with looking after Michelle's tracheostomy.

We used to dread the winter coming as with it would come the chest infections. I could not help but blame myself and think that each chest infection reflected some failure in my care of Michelle. We were very lucky in that we had a good back up system of understanding receptionists and doctors who would see Michelle whenever we were worried about her condition. Michelle was fortunately a very good patient and we were able to nurse her when she was ill with chest infections.

To relieve the tension that the parents of children who have tracheostomy's feel there is a definite need for a back up system of nurses who are able to baby sit for the parents and give valuable time in which the husband and wife can be alone together. It is unfair and often impossible to expect close family to baby sit as they often feel the responsibility too great and too stressful.

There were times when we wondered how we were going to carry on, but we realise that it would only be a short period that she would be very demanding and that the rewards of having her home with us far outweighed the inconvenience. The constant care and love she was able to receive from being home helped her to become emotionally stable and progress much quicker than she would have done in hospital.

(Michelle was the first child of a family living in north Wales. She was born with a meningocele at lumbar 2/3 level, which was closed, in Liverpool, on the second day. Hydrocephalus developed and also severe stridor one month after birth, which did not improve despite a shunt for the hydrocephalus. The tracheostomy was performed at 10 weeks of age and was required until Michelle was 2½ years old, at which time it could be closed. Michelle is now 6 years old and attends a school near her home—ed.)