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'We can't forget the frantic look on her tiny face'

Malcolm Blair-Robinson

Until October 1995 I had never given much thought to the NHS. I had hardly ever used it; I watched and listened to the political argument while sitting on the fence. Then early that month my wife, Mina, gave birth to our second daughter, Francesca, by emergency Caesarean. She has an elder sister, Karina, who is four. Even before the birth we knew that all was not well as an ultrasound scan had revealed a blockage in Francesca's bowels. When she was born it was also obvious that she had breathing problems.

Francesca was born in the local district hospital, a magnificent modern complex opened by the Queen herself, yet lacking, we were later to find, in essential facilities. The first of these was surgery for babies.

So, five days later, Francesca was transferred to the regional "centre of excellence", St George's in south London, for surgery to clear the blockage, while Mina came home to recover from her own surgery.

There is no more heart-rending experience for a mother than to return home from birth without her baby. But Francesca's intestinal operation was a success, and her bowel cleared, though there was still concern about her laboured breathing and low muscle tone. Her cry was silent, another peculiar feature.

In spite of these problems, Francesca was returned to our local district hospital so that Mina could visit regularly to establish breastfeeding before bringing the baby home.

This did not happen: after two weeks our daughter's breathing deteriorated to the point where her blood gases reached danger level and she was rushed by ambulance to the Brompton Hospital, London, which specialises in lung problems. Apart from X-rays, blood tests and a hearing test, no investigations had been carried out by the district hospital, despite her obvious difficulties breathing.

At the Brompton much happened with little result. A bronchoscopy (examination of the bronchial airways with a viewing tube) produced a diagnosis that later proved quite wrong. Our daughter was then transferred to Great Ormond Street Hospital for Sick Children, where her breathing problem was, within 24 hours, finally identified.

Francesca had a very rare disorder: the vocal cords, which control the windpipe as well as the voice, were paralysed, a condition probably caused by the baby contracting chickenpox in the womb from Mina at 14 weeks' gestation. This meant her airway was only half-open.

Doctors, however, thought she would probably be able to cope and at last, after seven weeks, Francesca was allowed home for the first time, a poignant moment. Six days later she was back in the district hospital because she was not thriving.

After a further two-week deterioration and lack of effective diagnosis, she was rushed to the regional hospital on a ventilator after suffering respiratory failure, there being no paediatric intensive care facility at the district hospital. Yet the intensive care unit (ICU) at the district hospital is enormous. Big enough to cope with quite a disaster . . . of adults. In view of this, it is astonishing that there are only three paediatric ICU beds at the regional hospital.

We stood together in disbelief as the crisis developed, with Francesca's breathing reduced to frantic gasps, her pulse rate dropping, watching doctors running hither and thither to mobilise equipment to snatch back a life plainly ebbing away.

Never will we forget the frantic expression on that tiny face as she fought to stay with us. We agreed that if all was lost, we would offer her organs at once in the hope of converting our despair to the gift of life for some other desperate family.

Medical attention at the regional paediatric intensive care unit was outstanding but shortlived. We were telephoned at 11 at night on the fourth day to be told Francesca had been taken off the ventilator and transferred to the paediatric ward because there was another child with an acute need.

The next day we were told that, in spite of Francesca's laboured breathing and oxygen dependency, she would be transferred back to the district hospital as the regional hospital needed her bed. A tearful plea to Great Ormond Street by Mina, who feared Francesca could not survive a further bout of medical ineptitude, persuaded that exceptional hospital to receive her as an emergency admission. She remained there for one month and finally came home four weeks ago breathing through a tracheostomy (a tube through an opening made in her windpipe) and feeding through a gastrostomy (a tube going direct into her stomach).

She is now making good progress and there is a 30 per cent chance that her vocal cords will recover spontaneously. We hope that later she will be able to have both tubes removed.

In four months we have learnt a great deal about medicine and the NHS. We are writing a detailed and lengthy report of our experience that will be sent to the relevant Parliamentary Select Committee. It will praise the medical and nursing excellence at Great Ormond Street, as well as the paediatric community nurses who have given us faultless support since Francesca has been home.

Most, but not all, of the rest of the criticism will be withering. Above all, it will argue that to centralise vital facilities at regional hospitals, while leaving major localities unserved, leads to little better than a fiasco.

Our personal experience of the system in traumatic circumstances exposed alarming weaknesses. The time has come for consumers to rebel.