

Author's Note December 2008

The following report was written at the start of Francesca's life and completed early in 1996. It has not been altered since. When it was written we did not know what her prospects were. In the event her life was an inspirational experience for her family and her friends. It ended, as it began, with her doctors, with the best of intentions, misjudging the nature of the help she needed them to give.

The report was accepted as a Memorandum of Evidence to the Parliamentary Select Committee on Health in the preparation of their own Report on Child Health in 1966 and a copy is retained in the House of Lords Library.

INTRODUCTION

This is a consumer's report on the shortcomings in the present structure of the NHS. It is not all bad news, however, and where praise is due, praise will be given. The narrative is informed largely by the experience of the first four months of the life of my infant daughter, Francesca Eugenie Blair-Robinson.

When my wife, Mina, was pregnant she contracted chickenpox at 14 weeks gestation, not having suffered from this almost universal disease when a child. Most unusually, Francesca's foetus was infected with the virus, causing marginal damage but with significant results.

She was born with a stenosis (narrowing) of a section of her small intestine, a left talipes (club foot) and very rare bilateral cord palsy. The latter is a paralysis of the vocal cords arising out of the failure of the two laryngeal nerves to transmit messages from the brain. The most obvious effect of this is a silent cry, symptomatic of the fact that the vocal cords are not moving to produce sound in the voice box. Unfortunately, the vocal cords also act to open and close the windpipe to facilitate breathing and to prevent the inhalation of food and liquids, including secretions and saliva.

In Francesca's case, the cords were static roughly halfway, meaning the airway is half open but also half closed. It is insufficiently open to allow satisfactory breathing, whilst at the same time open enough to allow the leakage of milk and saliva, resulting in foreign materials settling in the lungs, causing congestion and infection. This problem is exacerbated by the epiglottis valve not closing completely at the top of the throat, again allowing milk and secretions falling into the airway. It is assumed this is due to another faulty neurological connection from the brain.

Finally, the valve at the top of her stomach, which prevents food from coming back up the oesophagus once swallowed, is defective, allowing significant reflux. This is the term given to stomach acid and partly digested food rising back up the foodpipe to the point where, in Francesca's case, it can

aspirate into her lungs.

To combat these problems, various procedures have been employed.

To aid her breathing she has a tracheostomy, a plastic tube in her throat through which she breathes. Aspirating saliva and other secretions can be sucked out of the tube by a vacuum machine designed for the purpose. Tracheostomised babies require 24-hour care.

To prevent acid and part digested food from refluxing up the oesophagus, she has had Nissens funduplication, an operation that ties off the top of the stomach so that food can go down but not go back up.

To prevent her aspirating food into her lungs because her epiglottis valve is not closing completely, she is fed through a gastrostomy tube straight into her stomach, thus bypassing the malfunctioning area in the throat.

The narrowing in her small intestine was removed in a delicate 3-hour operation and the normal parts of the bowel joined together.

Two operations are planned on her foot when she is approximately 12 months old, after which the orthopaedic surgeon expects it to be cosmetically acceptable and physically functional, though a shoe size smaller than her other normal foot. Because the

chickenpox affects muscular development in a similar way to polio, we must accept the possibility that Francesca will limp.

After spending the first four months of her life in hospital, she is now at home, subject to the devoted 24-hour care of her parents and four year old sister, supported by the paediatric community nursing service. Her prospects are, at worst, that she will retain the gastrostomy and the tracheostomy for the rest of her life, and at best, that both will in due course be removed perhaps by the time she is ten, depending on the extent of neurological recovery. She may be able to speak normally, but maybe not. We have great faith in her own will to survive and prosper, and we look to the future with measured optimism, mindful of the obstacles to be overcome.

Part I is a step by step record of the diagnostic and treatment process which arrived at the outcomes set out above, and which exposed, both to me and my wife, the difficulties inherent in the present organisation of the NHS.

Part II is a review of the various elements of the NHS which we feel had an impact on our experience, set out under separate headings.

Finally, Part III represents our conclusions of what we found, under slightly different headings, together with recommendations under each heading of what action is called for.

In determining to what authority this report should be submitted, because of anxiety about the management structure of the NHS, we have concluded that the Parliamentary Select Committee on Health, with its powers to summon witnesses and consider evidence, would be the most appropriate. A copy has been sent to the Secretary of State for Health. A small number of additional copies have been distributed to interested parties.

This is not a report of experts. It is a report of consumers. Our intense exposure to the system over 120 days of continuous drama has given us an insight worth sharing.

PART I

THE SEQUENCE OF EVENTS

We were delighted to discover that Mina was pregnant early in 1995, and that the baby would be due at the end of October. Shortly after attending a wedding in Scotland, Mina contracted chickenpox from our daughter, Karina, then three. Although the disease can be quite serious in adults, Mina suffered no more than the average child with the infection, although she was anxious about the potential effect on the baby.

She was given assurances that there was virtually no risk to the foetus this early in pregnancy (14 weeks), and soon made a complete recovery. The pregnancy then proceeded uneventfully until the seventh month. By this time, she was much larger than at the same point in her previous pregnancy. The midwife recommended a second scan, the first routine scan at 20 weeks having been completely normal.

This second scan revealed that Mina was polyhydramnios, ie. her size was due to excessive water in the womb, not a large baby. Such a condition is not uncommon and did not give cause for alarm, but it was agreed Mina needed to be monitored regularly until birth. Measurements taken at the third scan indicated that the baby's growth, in weight, had slowed significantly, the water had increased and, more alarming, the radiologist spotted

distended bowels.

Immediate steps were taken to contact the gynaecological consultant, who arranged to see Mina the following day. The midwife advised Mina that she might be asked to attend St George's Hospital in southwest London where more sophisticated scanning equipment was available, and even conceivably if surgery were needed on the baby, to have an induced delivery at that hospital.

We saw the consultant who took the view that there was nothing to worry about ("second pregnancies are always more uncomfortable than the first"), that the bowels were not "*that* distended", that Mina should cancel the following week's check-up appointment and let the pregnancy go full term, returning to a clinic in a fortnight. Mina returned home in tears because she felt unwell and wanted instinctively to induce labour early.

In the small hours of the following morning, Mina woke to find her waters breaking, in fact it was a hindwater leak. The hospital was notified and an ambulance was sent. Mina could not be taken in a car because she had been advised by the midwife to remain horizontal on the journey due to the excessive amount of water in the womb. After consulting with Mina and taking into account the scan evidence that the baby had bowel problems, the doctor on duty agreed to induce labour. Mina was anxious that the baby be born as soon as possible, feeling worried about its

welfare.

Because Mina's waters had not, in fact, broken completely, it became necessary to break them artificially, subsequent to which an emergency arose whereby the umbilical cord began to emerge at a point when the baby could not yet be delivered (cord prolapse). Rapid and skilful action by two midwives and the doctor averted a crisis, but later tests showed that the baby was in some distress and an immediate emergency caesarean took place.

Within minutes Mina was in theatre, and a girl was safely delivered (Apgar score 7). A doctor and two nurses from the Special Care Baby Unit at the hospital had been present during the delivery, and they now brought her to the ante-room where I had been waiting. I was allowed to hold her briefly. She was a beautiful child and was sleeping peacefully. I was surprised I heard no cries.

I was told that she was to go at once to SCBU to be assessed and that I would be able to join her in about thirty minutes. Meanwhile, I returned to the labour room to collect Mina's belongings while she was taken to the ward to recover from the operation. Later, the doctor who had conducted the operation, the same who had monitored the labour, told me that Mina had come through very well, but he thought it likely the baby would be transferred to St George's for surgery that night.

After spending a little time with Mina, I was taken to SCBU where I was able to study Francesca closely, although she had been placed in an incubator for close monitoring. There appeared to be some problems with her breathing as she suffered desaturation while I was there, ie. the blood gas exchanging process was not efficient and therefore additional oxygen had to be given. The staff were in the process of arranging for X-rays to determine the difficulty in her bowel, and they confirmed that a transfer to St George's was imminent.

It now becomes necessary in this narrative to identify doctors individually, but I am reluctant to name names for reasons which will be explained fully in the conclusions section of this report. However, identification is important, so I will use the letters of the alphabet.

Francesca was now placed under the care of the paediatric consultant Dr A, although during this first evening, I met only Dr B, the Senior House Officer who had attended the delivery. Presumably, this was because Francesca had been born on a Saturday and the consultant concerned was not on duty that weekend. Over the next several hours, tests and X-rays were inconclusive. There was uncertainty whether her bowel was blocked or not. Francesca's breathing seemed laboured. She was floppy (poor muscle tone) and had vomited after sucking on a test bottle enthusiastically.

The following day she was seen by a consultant Dr C, who was accompanied by his registrar Dr D. Attempts by Mina to breastfeed were not really successful. Although Francesca latched on to the nipple and sucked well, she became quickly exhausted. Worse, bile-stained mucous and milk came out of her nose. Desaturation continued to be a problem.

Dr C noticed twitches which he felt might be fits, and an EEG was ordered. This showed no abnormalities. Francesca began to discharge mucus into her nappies, but it could not be determined for certain whether this had passed completely through her system or whether it was coming only from the lower part of the intestines with a blockage above. Further X-rays were taken as the consultant radiologist available was unwilling to administer a barium swallow or barium enema to so tiny a patient, although these seemed to be the only tests which could reliably determine what was happening in Francesca's digestive system.

Monday dawned without any resolution of the problem, though instructions were given that she could no longer be fed, as there was no certainty where the milk was going. The consultant to whom Francesca was allocated, Dr A, had not yet appeared on the scene because he was away. Because Dr A has an "interest" in gastroenterology, it was decided to wait until he could look at the X-rays before anything else was done. Dr C in the

meantime organised other tests, an ECG, a spinal tap, a blood screening test etc., to see if anything else manifested itself.

Dr C could not have Francesca transferred because it was not his patient. The tests were all negative, the read-outs were normal. By this time an intravenous line had been inserted and Francesca was being sustained by dextrose only.

Day 4, Tuesday, and Dr A finally arrives. He formed the opinion that Francesca's bowel was blocked and that surgery was necessary. Accordingly, she was transferred to St George's, Tooting, the following morning.

It is worth recording at this point that the diagnosis which had taken 4 days to reach was identical to that arrived at by the antenatal radiologist at the last ultrasound scan 24 hours before Francesca's birth.

Once at St George's, the diagnostic process proceeded apace. Francesca had been transferred from Guildford in the morning, and I drove the 40 miles to see her that afternoon. I was unprepared for the culture shock.

The Royal Surrey Hospital in Guildford is a modern building spread over an extensive site. Those parts of it to which I had so far had access, the maternity unit and SCBU, were fresh, well staffed, well organised and of a general care standard that would lead one to declare that the NHS was difficult to beat.

There was a creeping anxiety about diagnostic procedures, but at this stage they were only echoes at the back of our minds.

Although St George's is also a relatively modern building completed only 15 years ago, there is everywhere evidence of lack of resources. Gardens overgrown with weeds, grass coming up through the concrete, lighting tubes burnt out and not replaced, paint peeling off the walls. Everywhere there was an impression of resources pushed to the limit, heightened by the large numbers of people streaming through the corridors in every direction. It was clear that this was not only a regional centre but also a local hospital serving the immediate community, and this combination was evidently demanding.

The medical technology available in the neo-natal unit where I found Francesca was vastly more comprehensive than anything I had seen at Guildford. There was an urgency about the pace of events which for the first time seemed to equate with our baby's condition. Tests were decided upon and took place within minutes, not when this person was available or when that person came back from somewhere.

By the following morning, Thursday (day 5), the diagnosis was complete. Francesca had a blockage (a narrowing) in the bowel, revealed by a barium enema, the procedure refused at Guildford. Emergency surgery took place that afternoon, taking three hours. The surgical team was led by a distinguished consultant

of high and deserved reputation.

Francesca withstood the trauma well and the operation was a complete success. When Mina and I visited her the following day, the doctors were very pleased with her progress and the surgeon took time to spend some 20 minutes with us explaining the procedure in detail, and his expectation that the baby would make a full recovery. Francesca remained at St George's for 9 days in total. As soon as her digestive system could accept milk, the intravenous line was removed and a nasal-gastric tube inserted. This enabled nursing staff to feed Mina's expressed breastmilk.

It was now the difficulties in the structure of district general hospitals with limited facilities relying on regional centres of excellence began to emerge. Travel to the regional hospital, particularly in the overcrowded southeast with numerous traffic delays, was both time consuming and tiring. At night, the one way journey could be completed in as little as 40 minutes, but at peak times, it could take an hour and a half, making 3 hours for a round trip. This was no framework in which to establish breastfeeding when doctors gave the green light for this next step, but Mina and I were anxious that any outstanding concerns regarding other aspects of Francesca's physiology should be resolved before she left the hospital which had the resources available to make effective diagnoses.

Francesca continued to be floppy, although opinion varied as to

whether this floppiness was a natural consequence of her traumas to date or whether it represented a problem elsewhere. A consultant neurologist visited her but felt she was too young to be able to diagnose anything specific and that she should be examined again in 2 months time. An orthopaedic registrar examined Francesca's foot and reported encouragingly how this could in due course be improved by a combination of surgery and physiotherapy, but it was decided that as the intention was for the child to return to Guildford, she should be placed under the care of the orthopaedic consultant at the Royal Surrey.

Finally, we continued to express anxiety about Francesca's breathing, which appeared both laboured and exhausting. The general opinion at this stage was that this was caused by a floppy larynx, a condition that would allegedly explain both the breathing difficulty and the stridor we could hear. It would also supposedly explain her mute cry. Francesca went through the normal process of crying, as in a healthy baby, but no sound resulted, just a pronounced hiss of air.

We were not convinced and asked that some kind of detailed examination of her airway take place, perhaps a bronchoscopy. The medical authorities were inclined to agree but decided instead to test Francesca's blood gases first. The bronchoscopy idea was abandoned when these were found to be satisfactory. This measurement indicates how well the patient is clearing the blood of poisonous gases by the breathing process.

Throughout this period she was wholly inactive, lying prone in her cot without even the need to stir herself to feed as this was done by tube, and no measurement of her blood gases after exertion took place because there was no activity.

In spite of the failure to follow through the breathing question, enormous consequences of which did not become apparent until much later, Mina and I were impressed with the level of nursing care and medical expertise which we had experienced at St George's. We were surprised at the battered aspect at those parts of the hospital with which we became familiar. The worst feature was the parents' room in the neo-natal unit, described as a place where parents could relax and make coffee, tea etc.

This sanctuary turned out to be in a state of dereliction. The sink unit was missing, the sink and pipes for both the incoming water supply and outgoing waste were capped off. Water was obtained by a jug from the fridge. Some of the chairs which were broken were stacked up in the corners. It was difficult to imagine a less suitable environment for parents, often tearful and traumatised by upsetting events, to find comfort. An open letter stuck to the wall from the Head of Neo-natal Care, explained that the hospital trust had refused funds to make repairs and improvements and called for donations from parents.

We found this state of affairs shocking. It was therefore with

some relief that we greeted Francesca's return to the RSCH. We imagined it would be just for a few days so that Mina would have a proper opportunity to establish breastfeeding, since so far, although now 2 weeks old, the baby had enjoyed no opportunity to establish a normal feeding pattern.

When we visited Francesca shortly after her return, she had been briefly examined by two doctors we had not previously met, Dr E and Dr F. Dr E was another consultant. They expressed the hope that she would shortly thrive and be able to go home for the first time.

The following morning Francesca was seen by consultant Dr C, and it was agreed that the priority was to establish feeds and achieve an increase in Francesca's weight, which by this time had dropped considerably and was well under her birthweight. To assist in this, Mina was provided with a room for herself and the baby, so she could remain at night and feed throughout the 24-hour cycle. The facilities were excellent.

Unfortunately, the programme had to be abandoned after two days because Francesca continued to lose weight and seemed unable to complete a sufficiently long feed on the breast to meet her needs. She became a grey, dusky colour while feeding and would fall asleep before suckling a sufficient amount. It was thought this inability to feed properly may be due to weakness arising out of Francesca's traumatic experiences to date, and it was

decided to return to tube feeding (nasal-gastric) until she was stronger.

During the following week a number of tests were carried out, including a chromosome test and an ECG, but no genetic or organic disorder was revealed. It did become clear from discussions with Dr C that he feared neurological problems may be at the source of the feeding difficulty. Mina, who was continuing to take Francesca to her breast during daily visits in order to ensure that the baby did not lose its sucking ability while being fed by tube, became convinced that the baby was becoming exhausted with the effort of trying to feed.

The predominant medical opinion, however, was that she had a floppy larynx which was responsible for secretions accumulating at the back of her throat, and for her mute cry, and the general debility was the source of the feeding difficulty. Mina and I were not convinced and took time to study our Family Health Encyclopedia. We feared cerebral palsy, but although Francesca had had a traumatic birth, there was no evidence of the oxygen starvation which might produce that condition through brain damage.

In the course of looking up the symptoms of floppy larynx, we came upon an entry referring to the laryngeal nerves, of which there are two, each controlling one of the vocal cords which, in addition to producing sound through vibrations in the voicebox,

also control the opening and closing of the airway (trachea). We discovered that malfunction of these nerves would produce paralysis of the vocal cords, signs of which include breathing difficulty and loss of voice.

We put this potential diagnosis to the doctors, but whilst acknowledging it as a remote possibility, no action was taken to investigate further. Another frustration at this time was the absence of the orthopaedic surgeon abroad, as we needed his opinion as to the appropriate treatment for Francesca's twisted foot. The etiquette of medical hierarchy evidently made it impossible for any positive action to be decided upon in his absence, in spite of the fact that Francesca was seen by both his registrar and physiotherapist.

Fortunately, the intense programme of tube feeding halted the weight loss and turned the weight curve upwards, and it was decided after 7 days that once again Mina should try to stay in SCBU and establish breastfeeding. The medical team felt Francesca could not come home until she was seen to gain weight on breastfeeding alone. Mina was optimistic that she was in the last stage of the struggle to get her baby home.

After three days the project was once again abandoned, this time in more alarming circumstances, and a devastated Mina was sent home alone yet again. Francesca had not gained weight whilst breastfed, and moreover, appeared to be less well. Her colour

was grey, she was very inactive and looked exhausted. The head nurse felt it necessary to check her saturation levels on the saturation monitor, and to our horror we saw it was under 60% when it should be between 95-100%. Francesca was immediately put into an incubator with a significant amount of oxygen. Since she would not settle in the incubator, she was later fitted with nasal canulas to give her continuous oxygen. When checked, her lungs were crackly, and it was obvious there was a problem there.

Alarmed by this turn of events, we began to feel a sense of drift. Francesca was now 4 weeks old with the question of her viability unresolved, no reliable diagnosis of her condition, and worse, even a clear grasp of what her condition actually was. We begged for investigations of her airway to see what was going on, but whilst these were not refused, they were not attended to. Dr C was now on holiday, a situation we found out quite by chance in response to our enquiries as to why we had not seen him for a few days, and Francesca's case was taken over by Dr A, her consultant in the first place.

We met and held some constructive but inconclusive discussions.

In addition, the head of neo-natal care at St George's, who is Head of Paediatrics for the region, paid a quarterly visit to the Royal Surrey and saw Francesca. I made a point of being present that morning and stood with nine other doctors around our baby's cot, discussing all kinds of possibilities but

without, it appeared, initiating any positive action. More blood tests had been taken and the results were awaited, but the obvious physical investigations were not taking place. There was a feeling that Francesca should recover from her present supposed lung infection, for which she was being given three different antibiotics. Nobody knew what the infection was as the tests proved negative.

Francesca was left to press on, feeding by bottle initially, but then with top-ups by nasal-gastric tube when she could not complete feeds. Eventually, she was so exhausted that feeds were by tube only. She was not improving.

On Monday, 6 November (day 30), Dr A checked her blood gas levels, in particular the amount of carbon dioxide in her blood.

This was approaching danger level (8). We received a call from SCBU saying Francesca would have to be transferred to the Brompton Hospital in London the next day which specialises in disorders of the heart and lungs. Our anxiety at this deteriorating situation was softened by the fact that at this specialist hospital there would be the medical skill, equipment and testing facilities so that the cause of Francesca's difficulties could be properly diagnosed and effective treatment, or at least management, begin.

The following two weeks were a difficult time. The journey, whether by car through heavy traffic congestion, or by train,

was tedious, and door to door took up to two hours by either method. It was a sobering thought that journey times by both would have been significantly less and certainly more reliable before the second world war.

At the Brompton, Francesca's condition stabilised and her lungs improved, although there was still no diagnosis as to what exactly was happening. Numerous tests were carried out, some repeats of RSCH tests, all of which were negative. She suffered none of the infections or disorders associated with the lungs. We were told that she had some of the symptoms of many things, but not all the symptoms of anything.

There were frustrations. The Brompton has no orthopaedic department, and advice about Francesca's foot, over which through the long delays we were now becoming very concerned, could only be obtained from the Chelsea and Westminster Hospital nearby. Since Francesca was not well enough for travel, a planned day visit was changed in favour of a visit by the C & W orthopaedic team to the Brompton. They recommended no action until she returned to the Royal Surrey at Guildford.

Twice we were allowed to take Francesca outside into the open air for the first time, but although her condition improved, she did not seem to fully recover. She was taking feeds from a bottle but consistently needed topping up through a nasal-gastric tube (breastfeeding had now been abandoned). She simply

could not sustain herself naturally. To try and push her weight up, additives/calorie enricheners were put in the formula, but this resulted in vomiting. The breathing difficulties continued.

We once more pressed for invasive investigations, and it was finally agreed that Francesca was well enough to have a bronchoscopy, which involved having a general anaesthetic. This was carried out on Thursday, 16 November. The outcome of this was odd. The diagnosis was of an underdeveloped voicebox ie. narrowed airway, enlarged/swollen vocal cords and a floppy larynx, but the consultant concerned did decide to consult his colleague at Great Ormond Street. The upper airway is not an area the Brompton deals with, but GOSH is an ENT specialist, as well as representing all the medical disciplines for children at a world class level.

This produced a suggestion that Francesca should be transferred temporarily to GOS, so that their ENT team could carry out another bronchoscopy with more sophisticated equipment and give a second opinion. We were relieved at this development, not least because we were becoming exhausted with the anxiety and stress of a situation that had now lasted 6 1/2 weeks. This affected not only Mina and me, but our daughter Karina, then 3 1/2 years old. We decided at the outset to involve Karina as much as possible, rather than take the view that she should be shunted off to friends and isolated from the trauma. She

accompanied us on probably the majority of the hospital visits, came to know the nurses and to make full use of the play rooms on the wards. She was also a tremendous source of strength for us.

At Great Ormond Street we stepped into a new world. Here was a hospital geared exclusively to the needs of children, well versed in the anxieties of parents, skilled in the art of communication, and much less obviously fettered by the etiquette of medical hierarchy. Within 24 hours the consultant surgeon of the ENT department had identified a very rare condition called bilateral cord palsy. The consultant neurologist considered it likely that this had been caused, as had been the stenosis of the bowel and the malformation of the foot, by the chickenpox infection.

Initially, the prognosis was optimistic. Some children were able to manage unaided with this condition, others needed a tracheostomy. In Francesca's case the cords were static about midway. However, at this point her performance during bottle feeds seemed to indicate there was no significant aspiration, but her feeds were thickened as a precaution.

The other potential problem was reflux, where partially digested food and stomach acid rises up the oesophagus and perhaps spills into the lungs. A probe to test for this had been carried out at the Brompton and found to be negative. In the light of all

this, the medical team at GOS felt it would be best for Francesca to go home and experience for the first time in her life the stimulation and care of the domestic environment with the proviso always that we should return at once to the Royal Surrey at the first sign of any abnormality.

And so it was, on Saturday, 25 November, after exactly seven long weeks, during which one or both of us had spent almost every day in hospital, that our baby arrived home. For the first time our little family was complete.

It was only as we began to relax and recover that we realised the bilateral cord palsy, diagnosed at GOS within 24 hours, was essentially the same condition as the laryngeal nerve damage we had first suggested after studying the Family Health Encyclopedia some four weeks earlier. However, we believed that our ordeal was now over. We did not know that the worst was yet to come.

There followed six days of home management during which we felt that Francesca would fulfil the hopes of the medical team at GOS and manage her disability without assistance. The key factor was to enable her to thrive, since as she grew it was likely her difficulty would become more manageable. It was plain she loved the home environment with the colours, sights and sounds of domestic life which contrast so sharply with the necessary antiseptic regime of hospital.

We began to establish a satisfactory pattern of bottlefeeding and relatively undisturbed nights. We noticed as always that Francesca's laboured breathing was accompanied by gurgling from secretions at the back of her throat, but we now knew these to be caused by malfunctions in the area through the cord palsy. Swallowing appeared not to be a problem, as Francesca had a very strong sucking action on the bottle. There appeared to be some discomfort after feeds which was thought to be connected with wind. It was not serious.

Towards the end of the week, the secretions at the back of her throat seemed to get worse and her breathing noisier. At 3 am on the seventh day, Mina woke me to say that she was now very concerned about Francesca's breathing and felt she ought to take her down to the Royal Surrey to be checked, and at the very least, give her some suctioning to clear the growing secretions.

We had kept in touch with the nurses in SCBU, and when Mina rang that night, they recommended she take Francesca to Compton ward, the paediatric ward. After Mina had set off in the car, I rang SCBU to ask them to alert Compton to Francesca's background to avoid unnecessary delay. This they happily agreed to do.

From this point, the standards of medical and nursing care began entirely to break down in a nightmare chain of events which came very close to costing Francesca her life.

First, Mina received a frosty reception from the night nursing staff on Compton ward who kept her waiting for half an hour before anything happened, after which a House Officer appeared and spent one hour recording the details of Francesca's history as described by Mina. This information was inexplicably not already available in spite of Francesca having been born in the hospital and spending 3 1/2 weeks of her life there. This doctor did listen to her chest but was confused by the rattling sound from the throat, and thus was unsure as to the state of Francesca's lungs.

No treatment was prescribed, but in view of the time, it was now 5 am, Francesca was admitted and placed in her own cubicle with Mina. Early in the morning Dr F visited. He was one of the paediatric doctors whom we had previously met before the transfer to the Brompton, but he did not listen to her chest as he had no stethoscope with him. I arrived with Karina some time after 10 am to learn that although Mina and Francesca had been in the hospital for some six hours, no effective examination of the baby had taken place.

I exploded and said I was sick to death of the medical ineptitude of this hospital, unaware that the room was wired for audible monitoring of babies' cries, an irrelevant facility as Francesca is mute. We were shortly joined by a nurse and I asked her what was going on and why Francesca had not been seen. She replied in no uncertain terms that the doctors were busy

and that there were many other children more sick than Francesca whose needs took priority. We had to wait our turn. I responded that I would accept no excuse for this disgraceful breakdown of medical organisation and would she kindly fetch a doctor at once.

Shortly, a Senior House Officer, Dr G, arrived and said he understood I wanted a doctor to listen to my baby's chest. Mina and I explained Francesca's condition to him and the fact that she had been in the hospital since 4 am, it was now approaching 11 am, that we had brought her here in the apparently false expectation that we would receive help and advice, and if this was not to be forthcoming, we would take her home. He dutifully listened to her chest, but once again was unable to make an assessment because "he had not listened to her chest before" and therefore had nothing with which to compare. There were rattles but he was not sure where they were coming from. He said the consultant was on her way on the rounds.

Just before midday he returned with the consultant, Dr H, whom we had not previously met. She carried out an examination and thought Francesca had contracted bronchialitis, a common infection for that time of year and of which they had several cases on the ward. This, readers may remember, had been considered as a possible cause of Francesca's difficulties before she was transferred to the Brompton. It was decided to test for the RSV, the most common viral cause of bronchialitis

and highly contagious. Over the weekend, Francesca made no improvement and was put on a small amount of oxygen, through nasal canulas. At this point, she was taking bottle feeds.

We discovered there appeared to be a severe shortage of nurses, and parents were expected to supplement the gaps in the nursing facility. This is altogether a different concept to allowing parents to remain at the hospital and assist with the care of their children.

On the Sunday, Francesca was seen by Dr I, who added his opinion that bronchialitis was the difficulty, but by Monday morning we were becoming so concerned about the poor quality of the nursing care and the lack of objectivity in the diagnostic process, as well as Francesca's condition which was not improving, that I made an appointment to see her consultant Dr A. I saw him in his office at my request in order that I could speak frankly. This was convenient because Monday was his "office day". He had received no report, it appeared, since Francesca had earlier left the hospital to go to the Brompton, so I began by filling in the significant gaps in his knowledge of his patient's progress.

I then made a strong complaint about the inadequacy of the nursing arrangements in Compton ward when compared with the excellent arrangements in SCBU. He explained to me that there had been some closure of the children's facilities at Frimley,

another hospital in the area, which was increasing pressure on Compton ward, which, on the night of Francesca's arrival, had been operating a "no admissions policy". Nevertheless, he said he would have a word with someone and to make a point of seeing Francesca the following day.

I returned to the ward and reported all this to Mina. The following morning Dr J arrived on the rounds. So far she had not been seen by, nor her chest listened to, by the same doctor two days running, and Mina at once enquired the whereabouts of Dr A, Francesca's consultant. She was told that Tuesday was Dr A's "study day". When Mina pointed out that Francesca had been in the hospital for four days and still not been seen by her doctor, Dr J signalled her disapproval, explained that it was the hospital policy for the doctors to "take it in turns to do the rounds" and then left the room.

A breathless Dr A later did arrive to carry out a brief examination, although by this time X-rays had proved inconclusive. There were fluffy patches on the lungs which were assumed to be bronchialitis, even though the RSV test was negative. The state of affairs on the ward continued to be depressing. When Francesca's saturation monitor at times was disconnected and taken elsewhere, Mina asked how many were available on the ward. The shocking answer was **three** (there are 7 separate cubicles for babies alone).

During the next nine days, we lived in a state of mounting anxiety as Francesca appeared to make no progress. A nasal-gastric tube had been inserted for top-ups, as she no longer could complete a feed. Eventually, bottlefeeding ceased altogether as she refused feeds. No specific treatment was given at the RSCH, other than let the supposed infection take its course. An antiviral drug available was considered too unreliable to be useful, especially since Francesca was RSV negative.

Mina made several calls to the ENT department at GOS for advice, and it is to their very great credit that her calls were always returned by a doctor on duty within 30 minutes. They listened patiently as Mina described symptoms and gave advice as to possible responses. They recommended she invite Francesca's consultant to call them to discuss the baby's management, but when the offer was made to him, Dr A declined. He said there was nothing to talk to them about.

He did, however, contact the respiratory ward at GOS. An ambulance transfer had been arranged for Tuesday, 12 December so that Francesca could keep a pre-booked appointment with the neurophysiologist at GOS to have her nerve and muscle responses tested (part of the neurological programme to try and determine the extent of the damage potentially wrought by the chickenpox). Dr A arranged for Francesca to be seen briefly by the respiratory team. Mina accompanied Francesca. The test results

were satisfactory, indicating that the damage might be limited to the vocal cord area.

The respiratory team, who had a sight of the X-rays taken at RSCH, felt these were too inconclusive, although it looked like it could be bronchialitis. However, in view of Francesca's diagnosed cord palsy and visible breathing, and now feeding, difficulty, it was agreed that if Francesca did not improve by the next Thursday, 21 December, she would be transferred to GOS respiratory ward on that day. The respiratory team said they would then do a series of tests, like a barium swallow and another PH probe, to ascertain once and for all whether Francesca was refluxing (food coming up from the stomach and leaking into the lungs) and/or aspirating (food leaking directly from the mouth into the airway).

In view of the lack of progress at the RSCH, Mina had been pressing to be allowed to take Francesca home for the interim period until she could go to her reserved place on the respiratory ward at GOS. Francesca was being tube fed and was oxygen dependent, albeit a small amount, but her management could be done at home as an oxygen supply could be set up. The respiratory team at GOS were supportive of this idea, although cautious, but we had the date ahead if things did not work out.

Basically, Mina found having to spend all day, every day, in hospital, making sure Francesca was looked after, very draining and stressful. She felt that there was little point in this as

nothing was being done, no tests etc. Our 3 1/2 year old was also unhappy at how the family had been split apart.

Returning once more to the Royal Surrey, final preparations were in hand the following day to enable Francesca to come home, though there were problems. There were no saturation monitors available for home use, and one of these was essential for a child in Francesca's condition. We could see the difficulties, but Mina argued that as she was expected to spend the better part of every day in hospital, with no specific treatment being given, she might as well be at home in an environment where it was felt the child would have a better chance of thriving.

Relations with the hospital became quite strained at this point, since we were utterly fed up with their performance, whilst they tried to grapple with a number of bureaucratic requirements before Francesca could be released.

On Thursday, 14 December, Mina arrived at 9.30 in the morning to find Francesca in a visibly worse state. Laboured breathing had now turned to three-gasps-per-breath, she was pale and lifeless.

She was just lying in her cot with her eyes closed, gasping for air. Dr F was in the cubicle and Mina told him to contact the respiratory ward at GOS at once. It was clear Francesca could not come home. He said he would, but Mina had to wait for Dr A, as it was Dr A's turn to do the rounds on a Thursday, before this action could be confirmed. He did not appear until 11.00

am, and GOS was contacted at last at noon.

Unfortunately, the respiratory ward at GOS was full. We were told Francesca would have to wait until Monday, and maybe then there would be a place. Mina was very worried and told me later in the day, when I arrived with Karina for a visit, that she did not think Francesca was going to make it in her present state through the weekend. Past history had shown that once Francesca deteriorated, the process speeds up. She said as much to the nurse on duty.

Karina and I were with Francesca in her cubicle, at approximately 4 pm, when a staff nurse had been supervising Mina giving Francesca a tube feed. Ten minutes later, she began to desaturate. A doctor was sent for as an acute crisis developed, with Francesca's heart rate dropping. Although Karina had been such a tower of strength, and had been so keen to support her baby sister, it seemed right to remove her from such a fraught atmosphere, so I took her to the playroom. After a few minutes, I left her there with the other children and hurried back to find that by this time, the emergency team were working and Mina had been taken to another room, where I found her bravely fighting back tears.

We returned to the cubicle where her condition was said to be stabilised and a blood gas test was being taken. Dr F had arrived and taken charge, and it must be recorded, that whatever

may have been the diagnostic difficulty, his actions that afternoon and evening saved Francesca's life. She lay in her cot, breathing in frantic gasps, her tiny face creased in a frown, and her eyes bearing an extraordinary impression of pleading anxiety. It was decided that I take Karina home. As we left, I saw the Senior House Officer, Dr G, running towards us with a slip of paper containing the blood gases reading. I stopped to enquire, but he could not disclose the information until he had given it to Dr F.

It was approaching 5 pm as Karina and I left the hospital car park to make our way through the evening peak traffic 14 miles to home. By the time we arrived back, the answerphone was already bleeping. The message from Mina was bleak. Francesca's condition was acute, she was being transferred to the intensive care unit to be put on a ventilator. They had to wait, however, as this ventilator had to be made ready in SCBU and taken down to ICU on the ground floor, there being no ventilators on Compton ward. Her carbon dioxide level was twice the safe limit, ie. 14.58 when the safety range ends at 8 (which is where it had been when she was transferred to the Brompton). Would I take Karina to a friend and return at once?

By the time I returned to the Royal Surrey, Francesca was in the intensive care unit and Mina in the sitting room organised for relatives of those in acute condition in ICU. Mina briefed me on what had taken place, how although Francesca was in the ICU,

because there is no paediatric intensive care at the Royal Surrey, Francesca would have to be transferred that night. There had been difficulty in finding a bed, the ICU in GOS being full also, but there was a bed in St George's, Tooting. A team was on its way down to collect her. When I found Mina in that little sitting room, she was close to despair. She had not seen Francesca for an hour and the work of getting her attached to a ventilator was taking much longer than had been suggested.

We began to fear the worst. We were quite exhausted and felt the situation may be hopeless. We decided that if Francesca did die, we would offer her organs at once in case they could bring life and hope to other desperately sick children. We were greatly relieved when the director of the ICU came to tell us that Francesca had been stabilised and we could see her. It was an amazing sight to see this tiny form almost covered in tubes and wires, with her face almost obscured. What did strike us, however, was that she looked so peaceful. Her skin colour was more pink, but most of all, her chest was rising and falling with each breath as in a normal baby, rather than the gasping motion from the abdomen.

It was not long before the team from St George's arrived. This consisted of a registrar, an anaesthetist and a staff nurse, as well as two ambulancemen and a portable ventilator. We had to return to the sitting room whilst Francesca was now transferred to their portable ventilator, a process which took nearly

another hour. Finally, we set off in our car to follow the ambulance to Tooting in south London at 10 pm, some five hours after the emergency occurred. On the journey we discussed the previous two weeks and decided that something was seriously wrong with the system which had brought Francesca to her limits, when we had taken her on our own initiative to the hospital for help. I resolved, whatever the outcome, to prepare and submit this report to competent authority, and to try in whatever way possible to analyse where things were going wrong.

At St George's we found Francesca in the process of transfer from the portable ventilator to a hospital machine in the PICU.

We were astonished to find that there were only three beds in this unit which was the entire regional facility for children. The room was tiny and cramped with boxes of equipment on shelves all around the room, and the doctor's office, no more than a shoe box, doubled as a tea/coffee point, nurse's room and a place to keep essential supplies. Nevertheless, whatever the environmental shortcomings, they were more than made up for by the extensive equipment and above all by the excellence of the medical care. Both the nurses and doctors were outstanding, made us feel welcome, gave us chairs right by Francesca's cot and provided tea and coffee.

When we knew our baby had been stabilised, we set off home, arriving back at 1 am, completely shattered but comforted by the knowledge that at last Francesca was receiving the scale of

medical treatment she needed if she were to survive. Over the next few days, the doctors and nurses at St George's worked hard and Francesca's condition continuously improved. Her blood gases were now normal, but she had also been found to be anaemic. She was given a blood transfusion of 60 ml, after which her appearance improved significantly. Ironically, she was found to be RSV positive, so she had eventually caught, at the Royal Surrey, the virus that she did not have when first admitted to that hospital.

There were consultations between St George's and Great Ormond Street, because we explained to the doctors that Francesca had been due to go there on the Thursday, 21 December. The decision was made that St George's would not get involved and start carrying out investigations to determine what Francesca's core problems were. This would be determined by GOS, who were concerned to hear of her deterioration and dramatic exit from the Royal Surrey. The intention was that either Francesca would remain under intensive care at St George's until she was ready to be transferred to a ward at GOS, or possibly she might be transferred to GOS's intensive care unit. In the event, GOS still had no ICU bed available, and because of Francesca's fragile condition, investigations were to be left until after Christmas.

On the fourth day, Monday 18 December, we were telephoned at eleven at night by St George's who told us that they were having

to take Francesca off the ventilator and transfer her to the paediatric ward because there was another child with an even more acute need for a ventilator. They felt, however, she was sufficiently stable. I rushed up to Tooting to see her the following morning, and it was clear that although she was managing, she was having difficulty breathing. She was still oxygen dependent and tube fed.

We then learned that it was the intention to transfer her back to Guildford until after Christmas, again due to the pressure on bed spaces. This was too much. Mina, who had remained at home, telephoned Great Ormond Street in tears and told the ENT team there that she feared Francesca would die if she were returned to the Royal Surrey. She described in detail recent events and Francesca's current state, and made clear the need for an urgent tracheostomy. Her plea was heard and within an hour arrangements had been made to transfer Francesca to GOS on Thursday 21 December, but to the ENT ward where she had been assessed the first time.

When she arrived, they viewed her deterioration with some dismay and decided on an immediate tracheostomy for the next morning. However, she began to deteriorate, needing 50% oxygen to keep her saturation levels normal. There was uncertainty as to whether she would be strong enough to have the operation, so the intensive care team were sent for to give an assessment. They felt she was stable where she was but were on stand-by for

further deterioration.

Mina was very distressed, fearing that maybe Francesca had been pushed over her limits again and would need more ICU care, but to our relief and amazement, Francesca found some extra strength one last time and stabilised. The oxygen was reduced. The next morning the tracheostomy was performed, on Friday, 22 December.

From that point on, Francesca was the beneficiary of medical treatment and nursing care which surpassed anything so far experienced, except during the short stay in intensive care at St George's. The diagnostic procedure was focused and active. After the tracheostomy, it became clear that Francesca was refluxing food up from her stomach which necessitated a Nissens funduplication to eliminate it. Because a barium swallow also revealed that small quantities of milk were being aspirated into her lungs when feeding orally by bottle, we agreed to a gastrostomy, a feeding tube direct into the stomach. This was done at the same time as the Nissens.

An MRI scan showed that Francesca's brain was structurally complete and that there was no visible damage to the brain stem by the chickenpox virus. Her reactions and general alertness confirmed that there was an expectation that her mind was 100%.

We therefore hoped very much that when she finally came home, albeit feeding and breathing through plastic, she would nevertheless be able to develop as far as possible as a normal

baby and catch up lost ground. There is hope that she may improve sufficiently, with some neurological regeneration, for both tubes to be removed in time.

Finally, on 23 January 1996 Francesca came home. Her progress within the family of which she had battled so desperately to remain a member, has been dramatic. She needs 24-hour care to manage and supervise the special procedures which have given her a future. However, all her vital organs function normally and her inquisitive alertness indicates brain function of the sharpest kind. We know we are so fortunate in this respect, and even if Francesca has special needs for the rest of her life, in time that life can be both independent and of high quality.

She has bonded with us and especially her elder sister, and her smile lights up our world. It is our intention that that smile and the story behind it should bring light to the muddled thinking which has permeated much of the NHS management and the government from which it derives its authority.

PART II

REVIEW

Overview

The shortcomings we had encountered, as well as the successes, were very real. Their source was less clear. There was the human factor, but this, of course, can be misleading. An overworked nurse will appear less able than one who has time to care.

There were structural factors, in particular, the reformed structure of the NHS, the relationship between its purchasers and providers and the working of the internal market. I decided to research all these before reaching conclusions, as well as to investigate the relationship between the NHS and the medical profession itself. There were certainly some aspects of the medical profession and its hierarchical structure which appeared out of date.

As is the case with all things, powerful and inspired leadership can overcome a multitude of shortcomings to the point of obscuring the difficulties to all but insiders. On the other hand, leadership which is less inspired can not only expose difficulties which might otherwise be hidden, but create new ones which ought not to exist.

To make analysis easier, this part of the report will be broken down into sections covering the various areas, as will the final part dealing with recommendations.

The NHS Structure

The NHS is now organised on the basis that all, or almost all, hospitals are now run as self-governing trusts with a degree of independence, rather than as departments of an organisation with a central core. These self-governing trusts are responsible directly to the Secretary of State and not to the NHS Executive.

They provide "services" which are purchased on behalf of the community by purchasing authorities, known as Health Commissions. From 1 April 1996, these, too, will be responsible directly to the Secretary of State (though up till then they have been responsible to the regional health authorities) and will be known as district health authorities.

The regional health authorities, or remnants of them, are now merged into the NHS Executive. This, in its turn, is also responsible to the Secretary of State. The NHS Executive is in fact an organ of the Department of Health and is responsible for implementing policy laid down by the Secretary of State. The prime instrument for achieving this is to award what are known as corporate contracts to the revamped district health authorities to whom it also supplies the funds. These contracts are apparently not really contracts in the accepted sense, but agreed objectives and priorities, goals even, against the

performance of which the local health authorities are monitored.

The local health authorities are not, however, authorities in the sense that they have authority and give directions. They are purchasers of healthcare on behalf of the community in their area. They buy this healthcare from a variety of sources including hospitals which, in this contrived and so-called internal market, the hospital sells services to the health authority. The hospital is, however, a self-governing trust, and as such reports not to the health authority, but to the Secretary of State via another branch of the NHS Executive. The NHS Executive has responsibility for both the trusts and the district health authorities.

I spent considerable time and numerous phone calls to try and determine exactly how the management structure works. It must be stated that this structure changed from 1 April 1996 to a simplified layout, the most notable feature of which is the disappearance of the regional health authorities and their replacement by regional offices of the NHS Executive.

In Appendix 1, Mina has drawn two diagrams representing the old and new structures. Our experiences recorded in the first part of this report occurred, of course, under the old structure, although most of the changes are now in place and I suspect were probably working, certainly in skeletal form, at that time.

The primary feature of both structures is the concept of the internal market. This contrived and substantially artificial market is expected to exercise a degree of management control in itself in the relationship of purchasers and providers. For example, a district health authority would remonstrate with an NHS trust hospital if it did not come up to the performance levels set down in the contract for the provision of medical services. Direct management control, including the dismissal of officers of the underperforming trust does not, however, lie with the district health authority, but with the NHS Executive. Within the structure of the NHS trusts themselves (in the context of this report the hospitals), the medical staff are employed by the hospital trust and are responsible to the chief executive of the trust. However, this chief executive is obliged to defer to the medical staff on clinical issues. The head of the department, in the case of the Royal Surrey called a director in charge of a directorate, would therefore make his or her own assessment on a kind of self-reporting basis for the efficacy of medical decisions since the chief executive would be regarded as not competent to judge in these matters.

On the other hand, if the director felt that his directorate needed additional facilities as a matter of some priority, the chief executive would be obliged to refuse these if they did not come within the terms of the contract with the district health authority, since he would have no funds available. As we have all seen from numerous reported cases, there do not appear to be

sufficient funds even for some existing facilities to be fully utilised.

As the NHS claims to be the largest organisation in Europe with nearly a million employees and an annual budget in excess of £40 billion, it was disappointing to find so much effort was needed to define the lines of management control. It was also alarming that none of the normal enquiry points at any level could answer specific questions in this regard, either without research or at all.

In the end, I was sent by the Department of Health its own publication *Statement of Responsibilities and Accountabilities of the NHS* (from which Mina's diagrams are taken). This is 25 pages long, has 7 main headings and 33 subheadings. Even this does not make certain key issues clear, and following another call to the Department of Health, I was put in touch with a very senior member of the NHS Executive in Leeds. Though helpful, he could do no more than explain the structure. Neither he nor anyone else I spoke to showed any enthusiasm for the system.

The chain of command in the NHS in the conventional sense does not really exist. There appear to be various command structures operating in different directions at different times. Above all, the market with its all-pervasive contracts is designed to reduce the need for a command structure as markets are supposed to determine their own levels. If this were a real market

driven by customer choice, then maybe, but this market is not really a market at all, and though some degree of customer choice does perhaps exist in certain circumstances, it is in no way to be compared with shoppers going from stall to stall in a marketplace, handling produce and eyeing bargains.

Structure of Services

The Royal Surrey County Hospital, in spite of its title, is apparently graded as a district general hospital. It was built in 1980 and opened by Her Majesty the Queen. It occupies an enormous site and its construction employs the latest design features. Most people assume that it is a top hospital. There are in the area a number of community hospitals, but the Royal Surrey is the medical centre to which people expect to go in the event of serious need.

It is surprising to discover that in spite of an excellent maternity ward and an outstanding Special Care Baby Unit, there is no paediatric surgeon, and worse, there is no paediatric intensive care. The hospital boasts a large intensive care unit, well staffed, with a resident senior doctor styled as its director. The nearest paediatric intensive care is 35 miles away in south London at St George's Hospital, Tooting.

There has been much written about the inadequacy of paediatric care, and the subject has been well publicised on television.

The absence of a PICU at a county hospital of the size and importance of the Royal Surrey is the consequence of a policy decision to organise facilities of this kind at what were described as "centres of excellence". This policy, coupled with the absence of paediatric surgery, not only impairs the medical facility available at the hospital, but serves as a severe disadvantage to parents of sick children who find themselves transported to locations far from home, to unfamiliar localities, creating all manner of additional stresses, both to the patients, the parents and to their families.

The policy of closure of local community hospitals and the restriction of facilities at district general hospitals represents a policy approach which the general public who use the service find not only baffling but stressful. The official explanations sound at times more like propaganda in support of dogma than the outcome of thoughtful consideration and reasonable common sense.

The Medical Structure

Our experience in this respect was variable. At Great Ormond Street we found a coherent and easily understood medical structure where everything appears to be organised on a common sense basis, where medical teams are identifiable and accessible. The hospital is arranged in departments, neurological, respiratory etc. In our case, Francesca, who was originally referred to GOS by the Brompton, was perceived as

having a potential problem in the area of her throat. This proved to be correct, and because the paralysis of her vocal cords was identified as the core problem, she remained under the care of the ENT department and its medical team. Because she had other problems, she received attention from the gastric team for her Nissens funduplication and gastrostomy, from the neurological team for her MRI scan and continuing observation of her neurological development and from the orthopaedic department for the talipes. She was also seen by the dermatological team, who confirmed the blemishes on her skin as intrauterine chickenpox scars and took photos of them as this was the first time they had seen such a case. There were regular visits by the dietician, the development and orthopaedic physiotherapists and the feeding specialist.

At St George's we were, of course, at a regional hospital and not a specialist children's hospital, but nevertheless the medical structure appeared well focused with minimum inertia and able to cope speedily on our first acquaintance with Francesca's stenosis of the small intestine, which was operated on in 24 hours, and on the second occasion arising from her need to be on a ventilator. As Francesca was only on the paediatric ward during her second visit for 36 hours whilst awaiting transfer to GOS, we have no real experience of the medical care at this level.

The structure at the Brompton was easy to identify but less easy

to keep track of. The consultant who took charge of Francesca on her admission, under whose care she remained until her transfer to GOS, led a sizeable team of assistants which varied from day to day, though generally we were able to maintain contact with one or two registrars. The problem overall with the Brompton was that it is a specialist heart and lung hospital and Francesca had no problems with her heart, and her lung infections were symptomatic of a problem elsewhere, her lungs in their own right being well formed and healthy. After a time we seemed not to be getting anywhere with the Brompton, but they themselves identified this and transferred to GOS for further opinions. Overall, the Brompton was the wrong choice of hospital in the first place.

At the Royal Surrey we encountered a stream of shortcomings. In the early stages, the excellent environment, equipment and nursing capability of the Special Care Baby Unit was well ahead of the diagnostic capability of the medical team which supported it. No opinion could be obtained regarding Francesca's talipes because the consultant was in Australia and his subordinates were not authorised to act in his absence - an insulting farce.

Yet in spite of the really excellent nursing care available, she failed to progress and then began to deteriorate without any positive diagnosis as to the source of her feeding or breathing difficulties. A number of blood and swab tests were taken, all of which proved negative, but no formal investigation took place to determine what the obvious and visible mechanical problems

were.

A neurological problem was feared by one consultant, who went on holiday before his suspicion was formally pursued, though an outpatient appointment was made for Francesca to see a neurological consultant six weeks ahead. A floppy larynx, a comparatively minor defect in babies which normally corrects itself by age two, was thought to be the most likely cause, but once again no action was taken to convert the opinion into a diagnosis. A visit by the Regional Head of Paediatrics from St George's, part of a quarterly cycle, during which some nine doctors were gathered within the vicinity of Francesca's cot, produced no more positive action, though a plan was formulated to have a look down her throat some time the following week. Francesca's deteriorating condition intervened and she was finally transferred to the Brompton on Tuesday, 7 November, bringing to an end 18 days of humming and ha-ing by the medics and an exhausting period of anxiety and alarm for us.

To some extent the medical inadequacies had been masked by the excellence of the nursing care. This has been mentioned earlier and will be referred to later in greater detail. Mina and I began to feel that something was awry with the diagnostic process at the RSCH. Our confidence in the doctors themselves faltered because of the way they worked, exacerbated by the lethargic manner in which supporting services such as laboratory tests and specific examinations were organised.

This was driven home to us when after Francesca's readmission to the RSCH at 3 am on Friday, 1 December (after her 2 weeks at the Brompton, 4 days at GOS and 6 days at home), when it became slowly but ever more painfully apparent that an effective programme for reliable medical diagnosis in all but the most obvious cases had entirely broken down in the paediatric (Compton) ward of that hospital. Francesca's breathing difficulties were diagnosed as being caused by an attack of bronchialitis, in spite of the fact that two separate tests to identify that she was carrying RSV proved negative. Worse, the fact that she was now diagnosed as having rare bilateral cord palsy did not deter the doctors from jumping to the safest conclusion, ie. bronchialitis, without thinking about other possible causes like aspiration and reflux, which was, in the event, happening.

A major contributing factor in the failure to identify that a combination of aspiration and reflux was at the core of Francesca's difficulties was in our judgment without doubt connected by the fact that at that time, in that hospital, in that ward, there existed a bizarre procedure where all the various consultants and their teams took it in turns to examine the patients on their daily rounds. The consequence of this system was that it was not until the seventh day that the doctor who had first listened to Francesca listened to her chest again.

In the intervening period we had had to contend with remarks

such as "well, I have not listened to her chest before so I have nothing to compare". Unbelievably, Francesca was examined under this regime by no less than 10 doctors in thirteen days.

The stark absence of medical coherence finally ended dramatically when the struggling baby suffered respiratory failure on the afternoon of Thursday, 14 December. Just before this crisis, Mina had been so distraught by the lack of progress, that she was arranging to discharge Francesca, bring her home and take our chances with the care of our GP, an oxygen cylinder and the support of the paediatric community nurse. When it was proposed to return Francesca to the RSCH after she had been taken off the ventilator at St George's, Mina was convinced that Francesca would not survive.

Thus it was that Mina bypassed the medical system and made her dramatic appeal direct to GOS. It is to the everlasting credit to that hospital that within an hour, they had not only agreed to accept her but made all the arrangements. Francesca's mother will remain forever convinced that GOS's positive response just before Christmas, when the hospital was closed to all but emergency admissions because of the coming holiday period, saved her daughter's life. Although this is undoubtedly so, I believe it was Mina's willingness to bypass the system and take matters into her own hands regardless of the consequences which was the decisive factor in enabling this drama to eventually reach a happy ending.

The Nursing Structure

The first thing that has to be said about nursing is that it is the core of any healthcare system. Anyone who has experienced a period of acute illness or been beside a loved one who has, will know that nurses perform a unique function without which the concept of medical care within the civilised meaning of the term fails completely. It is alarming, therefore, to find at every point of enquiry the same dismal refrain: there is a severe shortage of nurses at almost every level.

Although during our 4-month experience of four major hospitals, when we saw nurses under pressure sufficient on occasion to impair the quality of their output, only once did we find the situation so bad as to make a protest unavoidable. This was in the Compton ward of the RSCH during Francesca's last period there in the first two weeks of December 1995. The confused response to that protest, and indeed the fact that no competent person could be found to protest to, made an investigation into the detail of that organisation, and nursing organisation generally, a must.

The first, and rather disturbing, discovery was that there no longer exists a nationally recognised nursing structure as was once the case. Readers of a certain age will recall the awesome authority of the hospital matron presiding over and responsible for the quality of her nursing corps supported by assistant

matrons, sisters and so on. There appears now to be no formally recommended structure. It is left to each hospital as an independent NHS trust to organise its nursing arrangements in a way it thinks best. Some will think wisely and involve a system which works well, but others will be less successful.

Our experience of the nursing at GOS was that it was outstanding. Mostly the impression was that there were enough nurses to give each little patient sufficient attention, and the contribution parents made was more to do with comfort or learning how to manage their child than supporting the nursing staff. One could leave that hospital with the absolute assurance that all the children were in the best possible hands.

The Brompton was satisfactory though not as good as GOS. There were times when the nurses did appear under pressure and not as well focused as either GOS or St George's. For example, one nurse in charge of the room thought Francesca was a boy and was due for heart surgery. Sometimes the named nurse would disappear for a spell without others knowing exactly where she went or when she would be back.

Our experience at St George's was almost entirely in either the PICU or in the neo-natal unit, both of which operated to the highest standards with sufficient nurses to give whatever level of care was needed. The situation seemed adequate in the

children's ward, though Francesca was there for only two days. When asked by Mina, the nurses were satisfied the ward was, on that day, reasonably staffed - they confirmed they had the number of saturation monitors needed.

In the Special Care Baby Unit at the Royal Surrey, the standard of nursing care matched GOS, which made the state of affairs we encountered later in the children's ward of the same hospital all the more incomprehensible. Here, at no stage, did Mina feel (with justification as it turned out) that Francesca was in safe hands, although the position was helped for a day or two when staff from SCBU were drafted in following my complaints.

As there is a relatively close working relationship between St George's, Tooting as the regional centre and the RSCH as the district general hospital, I have decided to look in some detail for the purposes of this report at the nursing organisation in each. First, St George's.

One must first of all remember that this is a huge hospital which has several departments as big, or almost as big, as smaller hospitals in their own right. However, the nursing structure is logically organised with a proper chain of command, starting with the Chief Nurse. The Chief Nurse, exactly as the title suggests, is the nursing supremo of the entire hospital. Reporting to the Chief Nurse are a number of Directors of Nursing. Each major department has its own director who works

closely with the clinical head who, because of the ever pervading need for managing the internal market and related financial issues, is supported by an administrative general manager. Thus, the nursing director fits into a team but then has an appropriate structure of control throughout the wards in the department. Some of the traditional titles have evidently been dropped. There are now Ward Managers rather than Ward Sisters, and even they have some business support because of their function as market operators.

This seems a logical and effective response to the current NHS structure, which, subject to the availability of staff, appeared to deliver results. Nevertheless, St George's, like everywhere else, is under pressure through a general shortage of nurses. Another factor, too, is that many who join the profession to nurse the sick shy off business responsibilities that come with being a Ward Manager and find this combination uncomfortable.

The second hospital we looked at in some detail was the Royal Surrey, not least because it was here that we had our worst experience, not only of medical competence but nursing care. As has been stated already, the quality of the Special Care Baby Unit is outstanding. Here a team of nurses operate three shifts in the 24 hours. They are lead by two senior staff nurses, each with many years experience in specialist baby care. In the children's ward, however, there seem to be not only a shortage of nurses, but a leadership vacuum. On one occasion we talked

to a Sister who appeared at our request, from whom it was clear the entire staff were harassed and overworked.

Following a disgraceful episode during which Mina and I had had to dry our sick baby in a blanket after giving her a bath because there were no towels on the ward, I had difficulty in finding anyone to get me a dry blanket to put the baby to sleep.

I demanded the Director of Nursing, which I understood was the modern title for matron. Nothing happened. On reaching home, I rang the General Manager to complain and was told that a very senior nurse (not the Director of Nursing for inexplicable reasons) would get in touch. I was shortly rung by a Senior Staff Nurse from the SCBU, whom it appeared had some overriding responsibility for nursing in the children's ward although she was actively nursing in the SCBU.

She did help to alleviate the situation by drafting down three SCBU nurses to help with Francesca's, and other babies', care when the baby unit was not too busy, but the whole command and responsibility structure seemed incoherent. For the hospital general manager and subsequently the clinical director and the chief executive to buck pass to this level of nurse, who could in no way be held responsible for what was going on, when they knew very well that lack of resources or mismanagement of them was the key, seemed to us disgraceful.

When taxed on the matter, the trust revealed that the

Directorate of Family Health was responsible for its own nursing organisation and that the Director of Nursing was *only there to advise* and to act as the statutory custodian of the professional quality of the nursing care. Cross-examination on this point at NHS Executive level revealed that whilst it was a statutory requirement for every trust to have a Director of Nursing formally responsible for the professional quality of the nursing, the job description of this board appointment was left up to each individual trust.

Some trusts clearly understood what they were doing and operated in the manner of St George's, Tooting, but others like the Royal Surrey have a far more opaque interpretation of what these duties are. Indeed, professional standard of nursing is a coherent quality marker only if there are sufficient of them, since the finest nurses in the world will not be able to maintain a professional standard if they are overstretched and overworked. There is no doubt, however, that shortcomings of this kind will be made all the worse if there is not a proper and coherent chain of command. Directors who are only advisers probably do more harm than good.

I had a useful dialogue with the Royal College of Nurses on this very point, and learned that they were becoming increasingly anxious at the emasculation of the responsibility of these new directors of nursing in many cases, which was contributing not only to a diminution in the quality of the nursing care, but also the absence of a motivational career structure which they

feared was impacting on both morale and recruitment. This worrying situation will be further developed in the conclusions and recommendations sections of this report.

Nurses' Salaries

It is not within the scope of this report to examine pay scales in the NHS, but as we were continually told that a shortage of nurses was a major contributory factor to a shortfall in standards or lack of facilities, it seemed worthwhile to take a brief look at the subject.

The problem was particularly acute in paediatrics where we were told there was a shortage of suitable candidates to be trained as nurses, and that if the candidates could be found the resources were not always available to pay them. A senior official at the Royal Surrey told me that attempts were being made to recruit nurses in Ireland. Afterwards I asked myself why not recruit from Germany or Switzerland? The answer, of course, was self-evident. Ireland, with one of the lower standards of living in Europe, would produce candidates who would be attracted to pay scales which would be dismissed by Swiss or German nurses. Nevertheless, Irish nurses are outstandingly good.

The Western Surrey Health Authority were kind enough to provide me with a copy of the nursing pay scales relevant to their own area. After a 3% increase in April 1995, the threshold pay

level was £7,549 per annum. In a multilevel pay structure it was necessary to rise 23 levels before the annual salary reached £15,000. The pay of nurses has been a contentious issue for decades. Whenever there is a clampdown on government expenditure, the pay of nurses always appears to be a candidate for economy, generating protest and controversy.

More recently, the concept of individual pay agreements with local trusts, eliminating a national structure for the profession as a whole, appears to have further undermined confidence among young people in nursing as a suitable vocational career. Of course, many nurses have such a strong calling to help the sick that pay is not a factor in their decision to join, but they, like everyone else, live in a real world and will in due course want to achieve a reasonable standard of living comparable to those friends who have sought alternative careers.

To properly staff the NHS with the required number of suitably qualified nurses, without which nursing excellence cannot be maintained, requires not only the services of the very dedicated but also of those who would have an excellent nursing capability if they judged it a career capable of fulfilling their financial and vocational ambitions. The historic notion that it is quite in order for senior consultants to become rich, and indeed, be provided with the means to achieve this, whilst expecting nurses to be satisfied to be poor at worst and marginally comfortable

at best, has done the provision of healthcare a great disservice.

Nursing is fundamental to healthcare. Everyone at some stage during their lives needs the services of this dedicated profession, and a revision of their status in the financial order of things is quite clearly long overdue.

The Internal Market

I have not the resources available to conduct an in-depth analysis of this unusual feature of recent NHS reforms, which very few people, even within the structure of the health service itself, appear to understand in its entirety and which most of the lay public do not understand at all. Most have a notion that it is somehow connected with traumatised patients lying on emergency trolleys for hour after hour while attempts are made to find them a bed.

I tried to discover whether the internal market was a cause of these difficulties, or whether its existence disguises the true difficulty, which is a lack of sufficient cash resources to do the job properly. In reality, I think both are true. There is undoubtedly a lack of resources overall, but the internal market makes these deficiencies more difficult to identify, and at the same time, ties up resources in its administration.

The general principle is that the NHS Executive, which is an

integral part of the Department of Health, allocates funds to the district health authorities via its regional offices which have replaced the regional health authorities.

The district health authorities are, in this fictitious market, the purchasers. They then enter into contracts with the providers of health services in the area they cover. Most obviously these are the hospitals, but it also includes ambulance services, home nursing care and other ancillary services. The district health authorities now incorporate the family health services authority, which previously looked after, and indeed employed, General Practitioners. Some of these are GP fund holders, some are not. Fund holding GP's are a sort of substrata of the health authority, receiving money to enable them to purchase hospital and other services for their patients.

If we examine the role of a district general hospital vis-à-vis a district health authority, it will give a broader idea of the working principles.

The hospital sets up shop to provide a range of health services up to a certain level of speciality and agrees a block contract with its district health authority specifying what these services are and for which the health authority will pay. Certain medical services may be excluded, for example, paediatric intensive care, either because the hospital does not wish to provide the service or because the district health

authority has decided not to pay for it at that point but to purchase the service elsewhere.

The hospital, which is a completely independent NHS trust, is not obliged to sell its services exclusively to its local district health authority. If it has a speciality available which is in demand, it can sell this to other health authorities. Equally, the district health authority can purchase outside its area for services that it deems within the scope of the needs of the population it serves.

The clinical decision to move patients from one hospital to another is normally taken by the doctors in charge, although ultimately the health authority always foots the bill. In anticipation of outside referrals, the district health authority will normally enter into contracts with regional centres to ensure that specialist care of a kind not available at the district general hospital, is available for its population further afield. If the district health authority has a contract with an outside hospital to provide this care, clinicians at the district general hospital do not have to seek prior permission to make use of the facility. If, on the other hand, the clinicians decide it would be best to go somewhere quite different, and it turns out the district health authority has no contract with the provider of that facility, then permission must be sought in advance unless it is a case of emergency.

Since the district health authority has no formal clinical capacity, any judgment it makes will be likely in individual cases to be influenced by cost. The district health authority does have the power to formulate policy within a given framework, and although it might be responsible for deciding not to arrange paediatric surgery and paediatric intensive care locally to its population, such an issue would be subject to the input of the NHS Executive as well. On the other hand, if the district general hospital decided that it was necessary to improve its paediatric care by providing a high dependency unit as a stepping stone between an ordinary ward and a full blown ICU, and this facility was not in its contract, it would have to apply for a variation to its contract before being assured of funds to meet the cost.

Once again, it is not clear what motivation informs this type of decision at health authority level other than budgetary constraints, since it makes a mockery of the concept of independent hospitals if they cannot organise the treatment of their patients in the way they, or in some cases even common sense, deems the most effective.

The relationship between the district hospital as an independent NHS trust, with a direct line to the NHS Executive, and the district health authority is opaque. The purchaser-provider element is clear enough, but whether it is the hospital which decides to offer the stall or the district health authority who

demands the goods is not clear, and neither could answer the question. Apparently, it was a matter of discussion, consensus and agreement.

Undoubtedly the market enables government to restrict resources to the NHS in such a convoluted way that the accusing public finger cannot easily be pointed at it. Indeed, when faced with a crisis, the Secretary of State can point fingers at the health authorities and issue directives requiring them to consider this and give priority to that, in the expectation of taking the political heat out of the question without having to come up with cash. A more direct system would make such a sidestep more difficult.

As a management system, the internal market is little better than an abdication of the concept, which perhaps is why it is necessary for the Department of Health to issue 25 pages of explanations as to how it runs this essential public service. As a market, too, it seems fatally flawed. Markets, to be effective, have to be free, otherwise they are more or less fictitious. They also require customers with the power to purchase or reject.

The customers of the NHS are, in the final analysis, the patients, who through taxation are paying the bills, but of course they are not customers in a conventional sense. They are people requiring a service in case of need. This is the nub of

the problem.

The NHS is not a business functioning in competition with other businesses, nor is it a market or a collection of markets, either free or fettered. ***It is a public service paid for by the public it serves, through contributions to the Exchequer via taxation.*** Clearly there must be a limit on its expenditure, otherwise the sky would be the limit, but there must also be an adequate standard and availability of service, reasonably accessible to the public who are paying for it. There must also be, because of the size of such an organisation, and this one is apparently the largest in Europe, tight management control.

The internal market is not a satisfactory instrument through which any of these goals can be reliably achieved.

Paediatric Intensive Care

Nothing better illustrates the flawed processes of the present structure of the NHS than the crisis surrounding paediatric intensive care. Although public pressure has caused the Secretary of State to issue, quite recently, a directive on this matter to the NHS Executive and health authorities, this report will pay some attention to this area of vital public concern.

We were astounded to discover that in spite of the presence of a resident medical director and extensive accommodation, the intensive care unit at the Royal Surrey was suitable only for

adults, and that any children or babies admitted were transferred elsewhere after initial stabilisation and as soon as a bed could be found. The nearest facilities were apparently at St George's, Tooting and Guy's in London. All three hospitals were at that time within the bounds of the South Thames Regional Health Authority. That body no longer exists, but the Western Surrey Health Authority, within whose boundaries the Royal Surrey operates, has entered into contractual arrangements with St George's for paediatric intensive care. Although St George's falls outside the Western Surrey's area, the arrangement is perfectly legitimate within the system.

Whatever sense this arrangement may make to planners, it makes no sense to parents. They mostly face severe logistical difficulties in travelling large distances on overcrowded roads to be with their desperately ill children. The strains felt by remaining family, which can include other small children left behind without sibling, or one or both parents, is significant.

When I enquired whether this state of affairs existed because the Royal Surrey had refused to provide the facilities, or whether it was because the district health authority refused to purchase them at that point, it soon became apparent that there were several conflicting pressures, including the nostrum that it was thought better to provide these facilities only at "centres of excellence". This had obscured completely the purpose of intensive care to the point where in a search for

excellence, tens of thousands of the population of western Surrey were denied a locally accessible facility altogether. This ridiculous thought process is akin to suggesting that those who cannot afford to purchase a Rolls Royce for personal transport should go without, rather than manage with a vehicle of lesser standard.

It is not entirely fair to blame the bureaucrats since many clinicians, keen to provide and work with optimum facilities of faculty standard, feel it is worth arguing for a concentration of resources. The administrators, faced with insufficient resources which have to be spread thinly, are keen on any project which will reduce cost, whilst the politicians wring their hands, blame everybody but themselves and hold the purse strings tight.

Because it is now no longer clear whether the NHS is supposed to be a business, a market or a service, decisions can become informed not by a clear vision of need, but by a toxic cocktail of conflicting pressures. One outcome is the alarming idea that unless intensive care can be provided at the optimum level, it is better not to have it at all. Obviously, at the optimum level it is very expensive and specialised and therefore has to be centralised. In a real world governed by the application of common sense, rather than the vagaries of a phantom market, the decision process appears more straightforward.

Clearly there are various levels of intensive care. In its most acute form, it will demand highly specialist skills and equipment and will inevitably be centralised. There may be major organic failure as a consequence of acute infections like meningitis, for which there are only a few specialists who can offer the prospect of effective treatment. At the other end of the scale will be an acute but potentially temporary condition brought about by a routine chest infection or an asthma attack, or perhaps an accident. Just as the district hospital provides an intensive care facility for adults in these circumstances, so it should provide for children as well.

I heard the excuse that if the facility was provided it would not be used sufficiently, as once again the shadow of the market blotted out wisdom. Intensive care is not like routine surgery.

Like other accident and emergency services, one hopes it will not be used. It is not expected that the fire brigade will be on continuous 24-hour call-out, nor that armed units of the police will be involved in gun battles on the streets night and day; rather that an emergency can be dealt with properly and efficiently before there is risk to life and limb.

Such is the case for intensive care of any age group, and the more especially for children because here it is possible to save a whole life. As age advances, it must be accepted that the number of years saved by prompt treatment will in the natural order of things not be many, but with an infant or a young child

there is a whole lifetime to celebrate, and this should demand an increased rather than reduced priority.

An organisation which is unable coherently to evaluate the priorities for little children is one whose analytical processes have gone sadly awry.

When one discovers, as we did, that the consequences of this policy was to have at the regional centre of excellence **only three beds** in a tiny room without natural daylight, imposing upon dedicated and quite superb staff additional operational pressures in what was almost certainly a daily fight for the lives of their little patients, the sense of frustration and anger was not easy to control.

Such was the case at St George's, Tooting. Whilst that hospital and its staff are quite blameless for this state of affairs, the policymakers who ordained it are guilty of conduct which approaches the level of a scandal.

The Professional Medical Structure

It is impossible to spend long periods in hospitals without becoming aware of the professional medical structure. Of course, almost every citizen is broadly aware that there is a professional structure, if for no other reason than there are so many medical TV dramas and factual programmes.

One of the worrying statistics to emerge in the news recently is that there is a potential future shortage of qualified doctors looming because of either lack of student recruits or students dropping out. It is not within the scope of this report to investigate the medical profession, which is a subject capable of inspiring a report of its own, but some thoughts have occurred to us which seem worth recording.

The development of the medical profession has been gradual over centuries, indeed, in various forms it is probably almost as old as mankind itself. Within our own historical context what began as a tribal wisdom, became in the early days of the profession a muddle of misconceptions which undoubtedly did more harm than good, before emerging into a distinguished science. One consultant with whom we had dealings remarked that medicine was a mixture of art and science. It is, I think, also true that in its day to day operation, it is rapidly becoming a technology.

Within that context, a strict hierarchical structure seems at times not only dated, but potentially inefficient. General Practitioners, or family doctors as they are often now known, appear to have one rank only. Some are clearly more experienced than others, but as soon as one steps into the institutional structure of hospitals, one comes upon a hierarchy with the consultant at the apex, beneath whom is the Senior Registrar, then the Registrar, the Senior House Officer and the House Officer.

The House Officer is the junior most recently qualified doctor who works by far the longest hours and is likely to be the first medical expert to be seen by anyone involved in a sudden medical emergency or accident. The pay at this level, which is the culmination of seven years study, is modest.

On the other hand, consultants can be treated as gods and worse, in some cases, treat themselves as such. Earnings will be very substantial, especially if private fees are added to the NHS salary (which is reduced by a twelfth if private fees are earned). It was our experience with Francesca that the lesser the hospital, the more pronounced the hierarchy. It is very noticeable at Great Ormond Street that the medical team of each department works as a team with a clear interchange of views and ideas, and accessibility at all levels. This demonstrated that the system works in enlightened hands, but with a clumsier touch, which was our experience elsewhere, we were left with a clear impression of out of date practice and inefficient use of personnel.

It is difficult to define who or what is responsible for the present order of things, which seems to have emerged with a life of its own over the years, not only here but overseas. Nevertheless, the NHS itself, the university medical schools, the Royal colleges, the General Medical Council as the statutory regulatory body of the profession, and the BMA as the voluntary

professional association, all go along with it. Confronted with the question why medical organisation in hospitals is *better* set up this way, none of these was able to provide a convincing answer.

Funding the NHS

It is clear that one of the purposes of the internal market is to try to organise on a competitive supply and demand basis the distribution of limited cash resources in the hope that efficiencies created by this market will limit the impact of an inherent shortage of funds. To use a health related metaphor, this is to treat the problem symptomatically without attempting to attack the source of the infection.

Funding the NHS has been a problem from its inception. Everyone who reads this report will be familiar with the pressures of the increasing cost of medical care for a host of reasons, and everyone will acknowledge the obligation of government of whatever political hue to prevent public expenditure spiralling out of control. There can, and should be, debate not only about the methods of such control, but also about priorities of distribution.

One of the difficulties which appears to afflict the NHS, perhaps not uniquely but this report is about that service, is the fact that no reliable estimate seems to exist as to how much it would cost to provide the standard and quality of service

which would satisfy consumers and adequately reward all those involved in its provision.

A second problem is the tradition of paying for this service solely out of general taxation revenues, so that the link which should exist between the public as paymaster and the public as consumer is for all practical purposes broken.

This leads to the third and irreconcilable problem that whilst evidence mounts of the underfunding of not only this public service but others, politicians engage in a competitive rhetoric about cutting taxes, in particular income tax. The outcome has been a culture in which the public simultaneously expects taxation to be cut and services to be improved. Whilst the drive for so-called efficiency can contribute to some extent to reconciling these apparently irreconcilable objectives, the point where a further significant contribution can be made by this method alone to improvements in the NHS has long since passed.

Government of whichever party will soon have to bite the bullet, discover what the true full cost of the NHS is likely to be, then face the electorate with a prescription for how this is going to be funded.

Public Accountability

Following the reforms of the NHS, the question needs to be asked:

through what instruments or organs does this service account to the public, and what access does the public have to bodies which can promote its interests in respect of the service?

The NHS Executive is part and parcel of the Department of Health and the executive of the regional health authorities is appointed by the Secretary of State. The community health councils, which are the official public watchdogs, were set up in 1974 to monitor the performance of a health service with a very different structure.

In these health councils, one third of the members are appointed by the local authority, but they do not have to be elected councillors. They can be, but on the other hand, the local authority can nominate other candidates of their choosing. A third of the places are set aside for representatives of organisations in the area which have an interest in healthcare and matters related to it. These voluntary organisations will be numerous and a ballot is organised among them to determine their representatives. Predictably, the final third of the members of the council are appointed by the Secretary of State.

Predictably, too, the community council has no actual power. It can complain, argue and request, but if the district health authority, whose performance it is monitoring, refuses, nothing more can be done except, of course, to appeal to guess who: the Secretary of State.

The district health authority itself is run by an executive, the members of which are appointed by the Secretary of State. The NHS trusts, which provide the services, though notionally independent, are responsible to the Secretary of State, and no forum appears to exist for democratically based criticism, opposition or comment other than the House of Commons in which a government with a working majority has little, in reality, to fear.

Whilst this state of affairs may be appropriate for running the armed services, for example, it hardly seems right for an organisation as personal to every member of the population as the NHS.

Private Healthcare

This report is about the NHS, not about private healthcare. Nevertheless, the two are entwined to an extent in that many consultants work for both, and following the introduction of insurance to cover the costs of private care, there has been a significant increase in this sector.

There is no reason why people, who can afford it, should not avail themselves to private medical care. Broadly speaking, the existence of a private sector should not be detrimental to the NHS, but there are some points worth making.

If salary levels in the NHS become unrealistic, some of the best people, particularly in nursing, may be tempted to move. If the relationship between the private sector and the NHS remains static, the movement will be limited, but if the private sector expands, the effect would be to diminish the quality of the human resources and indeed their numbers available to the NHS. This would be bad for the NHS and the future of healthcare in general.

There has always been some unease about consultants being employed by the NHS and running lucrative private practices in addition, but hitherto, the balance of public advantage has been judged as letting the present system continue.

There is a widespread nostrum that with the spread of health insurance companies, private health is more widely available and therefore consumers have a choice. This is not really true. The vast majority of contributions made to the biggest providers of health insurance in the UK are corporate, that is to say, company benefits given to employees as part of their remuneration package, though the market for private subscribers is growing. Only those who do not receive an automatic employee benefit of this insurance and have the money available to contribute on their own can be said to be freely making a choice, and they only because they have the money.

From a government point of view, this choice may be apt because

many of those benefitting from insurance either on their own initiative or their company's, would be likely to be among the eloquent critics of an inadequate NHS.

Most important of all, there is a flaw in the concept of health insurance in that companies refuse cover for illnesses or medical conditions from which applicants are currently suffering or have recently suffered. Additionally, premiums will increase as people get older and more likely to need medical care. A free society happily accepts the discrimination of pay, but the discrimination of need is less comfortable. The actuarial requirement of increasing premiums with increasing age at a time of life when there is probably an increasing need accompanied by a fall in income, indicates that insurance is not an adequate method for supplementing the NHS either by diverting demand to the private sector or by direct contribution.

Interestingly, although gross premium income rose steadily from £449 million in 1984 to £1.596 billion in 1994, the number of persons covered by private insurance peaked in 1990 at just over 7 1/2 million. In 1994, the last year for which I have been able to obtain statistics, the numbers covered dropped to just under 6 million. Value of claims covered in that year is £1.262 billion, which in the context of the £40 billion plus budget of the NHS indicates that the private sector as covered by insurance is still relatively tiny.

Later statistics will probably show some recovery in demand as the impact of the recession eases, but it is quite evident that the NHS is, and will continue to be, the overwhelming factor in the maintenance and provision of healthcare in the United Kingdom, as indeed it should be.

PART III

CONCLUSIONS AND RECOMMENDATIONS

Overview

This is an unusual report for two reasons. First, because it has been prepared by a consumer, rather than by a person or persons appointed for the purpose. Second, because it is based upon experience rather than an investigation.

This is not to say that extensive enquiries were not made once I had decided to embark on the project. They were. Nevertheless, the experience was concentrated in areas related to paediatric care, mainly within hospitals. Inevitably, this must narrow the focus of the report, yet I am satisfied that although the focus is narrow, it is sufficiently intense to highlight a number of flaws within the present structure of the NHS.

The object of this effort is to draw attention to these failings so that action may be taken, if necessary by legislators, to bring about improvements. The NHS is, even in its current fragmented form, a vast organisation which at one time or another touches all our lives. Its existence is central to the benefit of the state itself, and its function is critical to the well-being, and therefore the economy, of the whole nation. It abounds with dedicated and highly motivated individuals who strive selflessly to achieve the highest standards of patient

care and treatment.

Society owes to them the obligation of providing an environment in which they can give of their best without distraction. Society owes to itself the maintenance of effective standards at all levels, so that the call to need can be answered whenever the call comes.

1. The NHS

The NHS has become a fragmented structure providing a variable service available nationally. It is no longer a national health service providing a uniform standard of quality care everywhere.

***Recommendation:** Whilst allowing local initiative which benefits care, uniform minimum standards coupled with a firm national management structure must be established. This will require no increase in personnel or bureaucracy. The organs are in place in the form of the NHS Executive regional offices and the new district health authorities. It is their relationship with each other and with organisations which provide healthcare services which is both eccentric and unsatisfactory.*

2. Funding the NHS

The proper funding of the NHS is an issue which is central to

running it both efficiently and effectively. Achieving funding apparently on a limited cash basis from general taxation does not produce a satisfactory outcome.

***Recommendation:** A reliable costing is needed to establish what a complete, as well as adequate, standard of national healthcare would cost. It probably already exists somewhere under lock and key. With the figure known, the question of funding will have to be addressed. General taxation alone will not be suitable. A specific additional tax based on ability to pay, though politically unattractive, may be necessary.*

3. The Internal Market

The creation of the internal market to distribute limited resources is a device of great theoretical ingenuity but of little practical value. The dogmatic belief in markets by the political right is as constricting as the dogma of the old left

that planning would solve everything. The minor advantages of the internal market which relate to the ability of health authorities to purchase elements of healthcare from outside the NHS, or outside the area for which they are responsible, are far outweighed by bureaucratic eccentricities and distractions to medical staff.

***Recommendation:** The internal market be phased out. Those parts of its bureaucracy not required for line management and budgetary control should be disbanded, and any resources released applied to patient care.*

4. NHS Trusts

Whilst the concept of independent NHS trusts hold some relevance to major teaching hospitals and other centres of excellence, which, like great universities, will thrive upon their own independence and traditions, the devolvement of the concept right down through the entire structure of the NHS produces far too variable an outcome, much of which is unsatisfactory.

In particular, NHS trusts at district general hospital level, which should be the normal centre for both routine and acute healthcare for the population of that district, are neither satisfactory nor safe. The so-called independence of these units, constrained nevertheless by what they can sell to their district health authority, which in turn is constrained by the cash it receives from the NHS Executive, is a system which allows gaps in types of care as well as standards which puts lives at risk. ***This is not acceptable.***

Recommendation: *NHS Trusts should continue only at the level of major centres, whose resources and scope make the method appropriate. District general hospitals and related ancillary services should be reconstituted within an orthodox structure appropriate to a publicly funded service. Local involvement in management should be retained, in particular with the participation of democratic institutions.*

5. The Value of Nursing

The historic failure of the NHS to recognise and properly value the critical nature of the contribution made by the nursing profession has distorted both costing and planning probably for decades. The absolute refusal of the current government in its role as both fund provider and effective manager of the NHS to recognise this problem or even address it, is leading to a mounting crisis both of recruitment and personnel wastage. Time

and again facilities are closed or operating at a lower standard because of a shortage of nursing staff, leading to the stress and overwork of those who remain.

In the light of these circumstances, the current practice of awarding nurses a small pay increase nationally, which is far below that offered to other professional public servants, with a requirement that it negotiates locally for any improvement, is conceptually inept, damaging in effect and insulting to those who bear the greatest burden of patient care within the NHS.

***Recommendation:** An entirely new pay and career structure be established for the nursing profession, designed in the main by the profession itself which recognises the value to society of these dedicated people, and ensures not only an efficient working pattern but also buoyant recruitment. Adequate staffing levels is an urgent priority.*

6. Public Accountability

The level of public accountability of the NHS through democratic and accessible means is presently unsatisfactory. The power of the Secretary of State to appoint at all levels is excessive, and the absence of input by other democratic institutions at local level is alarming.

The only input I could find was at the level of community health councils, and even here, the one third of representatives who

could be appointed by the local authority were balanced by another third appointed by the Secretary of State. CHS's were set up in 1974 when the structure of the NHS was very different.

They do sterling work within their limitations but do not have sufficient authority to provide an adequate defence of the public interest.

Recommendation: *Public accountability must be improved to become more direct and less within the patronage of the Secretary of State. Revision of the management structure will help, but there must be a watchdog element to which the public has access and which has authority to require change.*

7. Medical Hierarchy

The hierarchical structure of the medical profession within hospitals (unlike general practice which is much more open) seems curiously out of date in a medical world increasingly dominated by science and technology. Rather like NHS trusts, it depends to some extent on who is involved. A consultant who is also a good leader will head a motivated team of registrars and house officers who interact with each other well, developing a group dynamic which will enhance performance. On the other hand, a consultant with an erratic personality coupled with

leadership failings will create tension in the team, leading to strains which will effect performance. We have experienced both outcomes.

Recommendation: *The General Medical Council should set up a working party drawn from all disciplines in the profession, as well as lay members, to consider how a more modern and responsive structure can be developed. In particular, the practice of using the excessive working hours of junior doctors as the foundation of medical attention should be phased out. This will require lateral thinking and a willingness to retain the tradition of excellence whilst abandoning some other, less well founded, customs.*

8. Paediatric Intensive Care

We had particular experience of the value of and the dangers in the absence of paediatric intensive care. The policy decision which has led to this was clearly informed by the wrong considerations. Whilst there is no doubt that it is desirable to maintain at certain key centres levels of paediatric intensive care which can, as a matter of routine, cope with any degree of trauma no matter how specialised or complicated, more local provision of what one might call basic levels of intensive care is a must.

Under the present system, the strain on the resources of those

centres which do provide the facility is acute, and the stress on families having to traipse around the countryside after their children demonstrates an unhappy lack of human compassion at the policymaking level.

Recommendation: *All district general hospitals should have, as a matter of the utmost urgency, both a paediatric intensive care facility as a department of the ICU, as well as a high dependency unit on the children's ward. Regional centres should provide PIC at exceptional levels of specialisation.*

9. Ancillary Services

Although this report has concentrated mainly on our experience of hospitals, the importance of all the ancillary services, most of which are now parts of independent NHS trusts, cannot be overstated. We have enjoyed excellent care from paediatric community nursing, community physiotherapy and of course our GP.

Nevertheless, we know from conversations with parents in other areas, that whereas some enjoy an even better service than we receive, there are others who are offered nowhere near our level of support by their local systems.

Once again, it is this element of chance, depending on location,

which is now an endemic feature of the fragmented NHS, which is not only unsatisfactory but unfair.

Recommendation: *There should be a standardisation of both the extent and quality of ancillary services, appropriately funded, and adjusted to suit local demographic population patterns.*

10. The Royal Surrey County Hospital

This might have started as a report about the Royal Surrey paediatric care facility, known in that hospital as the Directorate of Family Health, had it not become quickly apparent that wider issues concerning the overall structure and direction of the NHS were involved in the problems which surfaced locally.

It is a feature of the now devolved structure of the NHS, and devolved local management within that structure, that good leadership can give acceptable results within the restrictions posed by shortage of resources, whereas less skilful hands can produce a standard which is below an acceptable level. This is most certainly the case within the paediatric department at RSCH. The only strong feature is the quality of nursing in the Special Care Baby Unit. The children's ward has been variously

described to us by other parents who have had poor experience as between a shambles and a tip.

The nursing staff is overworked and of low morale. There is a vacuum of proper leadership of the nursing corps because of the practice at the RSCH of having a Director of Nursing who appears not to be directly responsible for the day to day operation of the nursing function. The Family Health Directorate has so organised itself that it has an excessive number of general consultants without any specialists whatever, who do not follow, in our experience and in the experience of others, a coherent pattern of clinical assessment and supervision, which leads to faulty diagnosis and unreliable treatment.

The absence of a properly equipped, high dependency facility, particularly important for children, and the total absence of paediatric intensive care serve to make matters worse. The decision over paediatric intensive care is probably outside the scope of the hospital trust, but the general level of organisation and competence is within its remit. It must stand heavily criticised for manifest failures, not only in performance but in its inability to respond when failures become evident.

This is not a criticism of the paediatric clinical staff individually, but the system in operation causes their performance as a group to be of a standard wholly inadequate to

the needs of the district. The relationship between the chief executive and his clinical directors, and the apparent requirement to defer to the clinicians on medical matters, creates a vacuum of management which in our case nearly cost a life, and which undoubtedly runs great risks. In departments other than paediatrics, the performance, from limited experience, appears reasonably satisfactory, making the failures in standards of childcare all the more disturbing.

Some of this may be in part due to the closure of paediatric wards in other local hospitals, causing overload at the Royal Surrey. Indeed, we encountered a "no admissions policy" in operation, though we were unaware of it at the time. This is wholly unsatisfactory.

It may very well be that these shortcomings exist in district general hospitals across the country, in which case they must be addressed without delay. In the case of the RSCH, the time for action is long overdue.

Recommendation: *The Secretary of State should, through the NHS Executive, review the whole structure of child healthcare at the Royal Surrey. In addition, a review of the level of childcare available at district general hospitals throughout the country should be undertaken urgently.*

11. Centres of Excellence

On the face of it, the concept behind the centre of excellence has merit: a regional hospital able to provide a very high degree of specialist skill for conditions which are both rare and highly demanding of both human and material resources. What must not happen is that district general hospitals have such a reduced capability that all manner of conditions which they ought to be able to treat have to be transferred elsewhere. The centre of excellence is then inundated with calls for treatment beyond its capacity to provide. This is particularly the case with children where once again, local capability appears quite limited.

Since it is now normal for at least one parent to accompany a child in hospital, and since often children have brothers and

sisters, the pressure on the family, as has been stated already, is significant under these arrangements, not to mention the inefficiency of providing medical care in this way. The only true centre of excellence we encountered has been Great Ormond Street, but even here many are turned away in acute conditions due to lack of resources.

***Recommendation:** Centres of excellence should be developed as required but without diminution of the proper level of adequate healthcare locally and within easy reach of each community.*

12. Great Ormond Street Hospital

No praise is too high for this hospital, its organisation, and its clinical and medical staff. It is difficult to grasp that not long ago a proposal to close it was halted by a public outcry. It demonstrates the value of medical centres with generations of experience and typifies the true concept of a centre of excellence.

***Recommendation:** Politically motivated decisions to close medical centres with generations, even centuries, of tradition should cease or be reconsidered. This is particularly the case if they serve a local population which would be required to travel outside its community in the event of closure.*

CONCLUSION OF THE REPORT

The NHS daily delivers a vast range of healthcare and saves countless lives. So remarkable are its achievements that criticism of any facet, particularly when it has saved the life of our child, might be considered uncalled for.

Nevertheless, the pressures upon its staff from its reformed structure very nearly cost us that life. Had it done so, both my wife, Mina, who has contributed to and edited this report, and I would have been too traumatised to undertake the task. Indeed, it might have been said, correctly, that the bitterness of grief had informed our judgment.

It is because Francesca survived the ordeal that we feel bound

to use the strength this has given us to bring into the open the need to restore the integrity of the National Health Service.